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# Treatment cost and access to care: experiences of young women diagnosed with breast cancer

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## Abstract

**Purpose—**Breast cancer is the leading cause of cancer-related deaths in women younger than 40 years. We aim to evaluate cost as a barrier to care among female breast cancer patients diagnosed between 18 to 39 years.

**Methods—**In early 2017, we distributed a survey to women diagnosed with breast cancer between the ages of 18 and 39 years, as identified by the central cancer registries of California, Georgia, North Carolina, and Florida. We used multivariable statistics to explore cost-related barriers to receiving breast cancer care for the 830 women that completed the survey.

**Results—**About half of the women (47.4%) reported spending more on breast cancer care than expected, and almost two-thirds (65.3%) had not discussed costs with their care team. A third of the patients (31.8%) indicated forgoing care due to cost. Factors associated with not receiving anticipated care due to cost included age less than35 years at diagnosis, self-insurance, comorbid conditions, and late-stage diagnosis.

**Conclusion—**Previous studies using breast cancer registry data have not included detailed insurance information and care received by young women. Young women with breast cancer frequently forgo breast cancer care due to cost. Our results highlight the potential for policies that facilitate optimal care for young breast cancer patients which could include the provision of comprehensive insurance coverage.

### Keywords

Breast cancer; Health insurance; Access to health care; Cost; Young adult

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**Conflict of interest** The authors declare that they have no conflict of interest.

**Ethical approval** This study was approved by institutional review boards at RTI, the Centers for Disease Control and Prevention, and each of the four central cancer registries that provided cancer registry data.

## Introduction

Although less than 5% of breast cancers are diagnosed in young women aged < 40 years, breast cancer is a leading cause of cancer-related deaths in this age group [1, 2]. Compared to women diagnosed with breast cancer after age 40, young women often report more cancer-related anxiety because of treatment-induced fertility changes, lack of age-appropriate information or support groups, and their attractiveness and body image [3, 4].

These young women may also be more likely to be uninsured or experience disruption in insurance coverage [5, 6]. Because young women are more likely than women aged ≥ 40 years to lack insurance coverage, receipt of optimal treatments may be lower in this age group [7].Even young women with insurance coverage may face challenges as copayments for cancer care can be high and they may not have stable careers allowing for continued benefits from employer-based coverage. They also may have accrued less lifetime savings, which could be used to cover outpatient costs. Young women may therefore face additional barriers related to cost when accessing quality cancer care than older women. Additionally, even among young women, those in the youngest age category (< 35) may face further challenges as they often have the most aggressive forms of the disease [8, 9].

Some women diagnosed with breast cancer need to continue treatment well beyond the initial 6 to 12 months of immediate cancer treatment [10, 11]. Treatment and other follow-up procedures (e.g., related to fertility changes) can continue for years after diagnosis. Women who experience disruptions in insurance coverage are vulnerable to discontinuing treatments or disregarding follow-up recommendations because of cost and, therefore, may experience suboptimal outcomes. We therefore need studies that can capture cost over the longer course of treatments required by many breast cancer survivors.

This study’s objective was to evaluate access to care among young women who were diagnosed with breast cancer, with a specific focus on cost as a barrier to receiving care over multiple years from the time of diagnosis. We analyzed data from breast cancer patients diagnosed at ages 18 to 39 years, who responded to a survey administered in early 2017. The sample was drawn from four central cancer registries. We systematically explored barriers to receiving breast cancer care among young women.

## Methods

### Study sample

We included women who were diagnosed with breast cancer between the ages of 18 and 39 years. We chose California, Florida, Georgia, and North Carolina, as these states have relatively large numbers of young breast cancer patients across all major racial groups. We included women who were (1) diagnosed with ductal carcinoma in situ (DCIS) (D05.90; 8500/2) or invasive breast cancer (C50; 8500/3) between January 2013 and December 2014 and (2) alive at the time of data extraction, as determined by state cancer registries, state death records, and the National Death Index, a national database compiled by the National Center for Health Statistics (ICD-10; ICD-O-3) [12, 13].

## Questionnaire design and content

The conceptual model presented in Fig. 1 guided the questionnaire development. In this manuscript, we focus on specific components related to insurance status, access to care, and cost. Patient characteristics and health system factors affect continuity of coverage, which in turn affects access to care and quality of care process. Decreased access to care can come from structural barriers (i.e., access to providers) as well as financial ones (i.e., cost-sharing requirements, lack of insurance). In developing our survey instrument, we emphasized questions that had been previously tested and fielded among breast cancer patients [14–17]. To further improve our instrument, we performed cognitive testing with nine English-speaking and eight Spanish-speaking young breast cancer patients.

The final instrument, in both paper and web-based formats, consisted of 66 questions, with an average completion time of 22 min (based on time required for individuals who participated in the cognitive testing of the questions). Six questions on insurance sought to characterize the extent of coverage during breast cancer diagnosis and treatment, as well as the respondent’s current insurance status. Eleven questions covered topics like out-of-pocket costs, financial decline, and cancer-related expenses, while 13 questions pertained to job-related topics like benefits and employment status. Ten questions addressed access to breast cancer care, and seven focused on quality of care. The remaining questions addressed the subject’s quality of life, demographic information, and cancer history. Question types included dichotomous and multiple response.

## Data collection

We obtained contact information for the breast cancer patients meeting the study selection criteria from the state registries in California, North Carolina, and Florida. Because of registry operating procedures, the Georgia Cancer Registry could not share address information with the research team. For all cases identified in Georgia, the cancer registry staff conducted the mailings in close collaboration with RTI International to ensure standardized procedures were followed. The first mailings for all states were sent in March 2017. The 3,659 young women met the study eligibility criteria and 2,927 women were alive and had deliverable addresses. The initial mailing included a cover letter, survey instruments in English and Spanish, and instructions for accessing the Web version of the survey. Respondents could choose to complete either the paper survey or the Web-based version. We offered a $10 gift card to those who completed and returned the survey. Reminder letters were sent to individuals who had not responded within 2 weeks, and a complete mailing (with the survey instruments) was sent to those who had not returned the survey after 2 months.

At the end of the data collection period in July 2017, 128 of the surveys had been completed online, and 702 had been completed by mail (830 in total), yielding a response rate of 28.4%. All surveys completed online were automatically uploaded into a dataset within RTI’s Hatteras Survey System. The paper survey responses were scanned, interpreted, and verified using TELEform software, an automated data collection system (Cardiff Software, San Marcos, CA). Ultimately, the Web-based and mail responses were combined into a single dataset, which was used to assess data quality and conduct statistical analysis.

## Statistical analysis

We created demographic variables from the information reported in the survey. Age at diagnosis was stratified to determine differences between those diagnosed at ages 18 to 34 years and ages 35 to 39 years, because of issues related to fertility preservation. Participants were instructed to select as many racial categories as applied. All other variations of more than one race resulted in a coding classification of “other.” Those who selected “Hispanic” regardless of race were categorized as “Hispanic.” The race/ethnicity variables are “white only (non-Hispanic),” “black only (non-Hispanic),” “Hispanic,” “Asian/Pacific Islander (non-Hispanic),” and “other (non-Hispanic).” We categorized marital status into three groupings: single, married or living with a partner and no longer married. For education, we report graduate degree, Bachelor’s degree, some college and high school or less. Insurance status is categorized as private (employer based), self-insured, Medicaid or Medicare, uninsured and other. Self-insurance is defined as individual coverage that is obtained through the private market or state exchanges and not through an employer.

Respondents reported the presence of 34 comorbid conditions, including cardiovascular, circulatory, diabetes, asthma and other breathing problems, vision, depression, migraines, back problems, arthritis, and thyroid conditions. We used these responses to create a variable indicating the presence of no conditions, one condition, or two or more conditions. The stage at diagnosis information collected through self-report in the survey was based on the American Joint Commission on Cancer [16]. We also created variables for insurance and employment status at time of diagnosis. This manuscript presents descriptive statistics of breast cancer care-related costs as well as multivariable analysis of forgoing any breast cancer care due to cost.

We used survey weights to compensate for the complex survey sampling design (i.e., unequal distribution across the states) and nonresponse. This weighting was intended to make our results reflect the distribution of the breast cancer patients in the four state cancer registries. We conducted a response propensity analysis of the response rates in each of the four states using logistic regression. These rates deviated only slightly across state—27.9% in California, 28.2% in Florida, 29.3% in North Carolina, and 28.6% in Georgia. The propensity analysis showed that, although response rates were similar in each of the four states, women from racial/ethnic minority groups were less likely to complete the survey. In regressions controlling for state, race, age, stage at diagnosis and treatment, non-Hispanic blacks (Odds Ratio (OR) 0.57) and Hispanics (OR 0.41) were less like to respond to the survey compared to non-Hispanic whites.

To adjust for potential nonresponse bias, we created and applied survey weights to the responses. The survey weight for an individual respondent is equal to the mean response rate divided by the propensity-predicted response rate for that individual. The adjustment process down-weights the responses of non-Hispanic white women compared with those provided by the other racial/ethnic groups in our survey and makes minor changes for small differences among the states.

In our descriptive analysis, we present the impact of cost on breast cancer care and the proportion of respondents who had to forgo specific types of care and follow-up procedures due to cost. We used logistic regression to evaluate the association between the respondents' characteristics and risk factors at diagnosis to the likelihood of forgoing care due to cost. The dependent variable was specified as not receiving health care services due to cost; independent variables of interest included age, race/ethnicity, marital status, educational level, comorbid conditions, insurance status, and employment status. The model included the American Joint Commission on Cancer stage and state of diagnosis as control variables.

This study was approved by institutional review boards at RTI, the Centers for Disease Control and Prevention, and each of the four central cancer registries that provided cancer registry data. Data collection approval was also received from the Office of Management and Budget (No. 0920–1123). All analysis was conducted using Stata statistical software, Release 15 [18].

## Results

Table 1 summarizes the clinical and demographic characteristics of the 830 respondents who were surveyed 3 to 4 years after initial breast cancer diagnosis. Overall, 60.5% of the respondents were 18 to 34 years of age at the time of diagnosis, and 39.5% were 35 to 39 years of age. Non-Hispanic white (48.1%) was the largest racial/ethnic group, followed by Hispanic (23.9%) and non-Hispanic black (17.9%). The respondents also tended to be well-educated and married—more than half (57.4%) of those surveyed had at least a bachelor's degree, and almost three quarters (71.1%) were either married or in a domestic partnership. In terms of clinical characteristics, more than three quarters (77.7%) reported at least one comorbid condition. About a third of the respondents were diagnosed when their breast cancer was at stage 0 or I (31.5%). Slightly more were diagnosed at stage II (35.4%), and slightly fewer were diagnosed at stage III or IV (28.3%). In terms of financial features, almost three quarters (73.4%) were employed, and about two-thirds (67.2%) had private insurance. Other forms of insurance coverage included Medicaid or Medicare (10.8%) and the self-insured (7.3%). Overall 8.6% were uninsured. Respondents who were diagnosed in California and Florida made up a preponderance of the sample (32.7% and 29.7%, respectively), while respondents who were diagnosed in Georgia (19.1%) and North Carolina (18.6%) made up similar proportions.

Table 2 presents the survey results that pertain to the cost of breast cancer care and its impact on decision making. Most respondents (77.9%) felt that health insurance covered "more than expected" or the "expected amount" of their breast cancer care costs, while about half (47.4%) reported that personal spending was "more than expected." Almost two-thirds (65.3%) reported that they had not discussed cost with their care team, and most (68.7%) responded "not at all" when asked whether they had considered cost in selecting a treatment course. Only 8.7% of the respondents had thought "a great deal" about the cost of their breast cancer care.

We categorize our survey respondents according to their reported level of difficultly accessing care deemed necessary by their doctor. Most respondents (67.7%) reported that access to care was "not a problem," but about a quarter (23.1%) felt it was a "small problem," and 8.2% felt it was a "large problem."

Figure 2 describes the treatments, medications, and appointments that subjects had to delay or forgo completely because of cost. “Miss a doctor’s appointment” (14.7%) was the most frequently cited, followed by “forgo fertility preservation” (11.9%), and “delay or forgo breast reconstruction” (10.9%). Some respondents had to forgo prescribed medications (7.3%), another 6.2% had to reduce medications, and 4.2% had to delay or stop treatment completely. Overall, about a third of the patients (31.8%; reported in Table 3) indicated some reduction in health care services due to medical costs.

Table 3 reports the results of our multivariable analysis to explain factors related to forging any breast cancer care due to cost. Respondents aged 18 to 34 years at diagnosis (odds ratio [OR] 1.51) had greater odds than older respondents of delaying, terminating or forgoing prescribed care because of cost. Multiracial subjects and those who selected “other” race/ethnicity had greater odds (OR 2.67) of forgoing necessary care, but there were no other differences across other race/ethnicity groups. Patients with one (OR 2.25) and two or more (OR 3.00) comorbid conditions were at greater risk of not receiving care compared with those without comorbid conditions. The self-insured cohort (OR 2.04) had higher odds of not receiving all breast cancer care than those with private insurance. Those covered by Medicaid (OR 1.33) and those who were uninsured (OR 1.34) did not statistically differ from those privately insured. Differences did exist between states; however, respondents who were diagnosed in California (OR 0.61) were less likely than respondents from North Carolina (reference state) to forgo care because of cost. Georgia and Florida had similar levels of access as North Carolina.

## Conclusions

In this study, we surveyed young breast cancer patients to understand the challenges they may have faced in accessing treatments. More than half of the breast cancer patients had a college degree, and two-thirds had private insurance. Less than 10% indicated that they were uninsured at the time of their cancer diagnosis. Even among this highly educated and insured population, we found that a third of the young women had delayed, postponed, or forgone care. Importantly, some had forgone fertility preservation and breast reconstruction, which have been reported in the literature as key factors affecting the quality of life and well-being of young women diagnosed with breast cancer [18–23].

Several factors significantly impact access to breast cancer treatments and other care. Women younger than age 35 years at the time of diagnosis are among the most vulnerable; although some programs are tailored to deliver care to this population, more support is needed [3, 24]. In our study, we observed that forgoing or delaying care was almost double when the breast cancer was diagnosed at a late stage or with other comorbid conditions, or when the woman was self-insured compared with those who had employer-based private insurance. For the latter, forgoing or delaying care could be due to insurance coverage, deductible, and copayment differences. For instance, existing literature has found that individual plans often include higher deductibles and out-of-pocket maximums than group plans, and individual plans displayed almost twice the average premium for 25-year-old consumers [24]. We found that young breast cancer patients in California (specifically South and Central regions of the state) were more likely to receive breast cancer services than those diagnosed in North Carolina. This finding indicates potential state-level differences in insurance coverage and access to breast cancer care that need to be further evaluated in future studies.

Most of the young women indicated that insurance covered as much as they expected of their breast cancer care cost. However, half also reported that personal spending on breast cancer care was more than they expected. Only one-third had discussed cost of care with their physicians, and only a small proportion (< 10%) had a great deal of concern about cost.

Almost half of the young women experienced negative financial impacts due to their breast cancer diagnosis, but many did not actively seek information on the cost of treatment to reach informed decisions about their care. Physician–patient communication barriers are widespread among cancer patients, not just young women with breast cancer [25]. However, young women (≥ 30 years) were found to be particularly at risk if their symptoms were normalized or dismissed by a healthcare professional before the underlying cancer could be diagnosed [26]. Given the unique challenges and treatments required for young women, targeted interventions may include components that foster provider team and patient discourse, promote cost transparency, and link young women with online or community-based financial support services.

This study has a few limitations. First, the survey response rate was less than a third of the targeted young breast cancer patients. Although weights were applied to account for those who did not complete the survey, this nonresponse could still introduce bias. Young women with breast cancer are a hard-to-reach group, and prior surveys have reported response rates in this range or lower [27, 28]. Second, our results are based on self-report, and social desirability bias could have prevented respondents from reporting on undesirable facets of their financial status or needs that cast them in an undesirable light. Third, respondents were targeted 3 to 4 years after their initial breast cancer diagnosis, and therefore, there is potential for recall bias in terms of breast cancer services and cost. We believe that any bias is minimal, as many women were continuing to receive treatment (specifically, hormonal therapy) and many survey variables showed moderate to high concordance when cross-referenced with the available cancer registry data. Furthermore, in terms of cost, the focus of the survey was not on obtaining the actual dollar amounts expended but rather on the impact of perceived cost on breast cancer care decisions. Fourth, we could not include women who died in the years before the survey was fielded and this could lead to an underestimate of the impact of cost on optimal care receipt as these women may have more likely to forgo care. Finally, while we focused on factors related to cost, other aspects, such as side effects of medications and comorbidities, could also result in women forgoing care. We measured comorbid conditions at the time of the survey administration, but some of these conditions could reflect longstanding conditions while others could be more recent.

This study adds new insights into financial access issues faced by young women diagnosed with breast cancer. We found that breast cancer patients who were < 35 years at the time of diagnosis had different complexities than patients diagnosed between the ages of 35 and 40 years: They tended to be diagnosed at later stages in the disease, be less financially secure, and more frequently forgo care. These factors can have compounding effects for young women, which can impact both their clinical outcomes and their quality of life. This study highlights the need for open patient and provider team communications about the cost of care and the benefits of insurance coverage; it also raises the possibility of targeted health care-related financial assistance, particularly for young patients. A key strength of this study is its ability to identify the characteristics of those who may benefit most from financial assistance or detailed information on breast cancer care costs, which includes younger women, those with comorbid conditions, and patients with late-stage diagnosis. These findings could help inform future programs and research initiatives in these areas.

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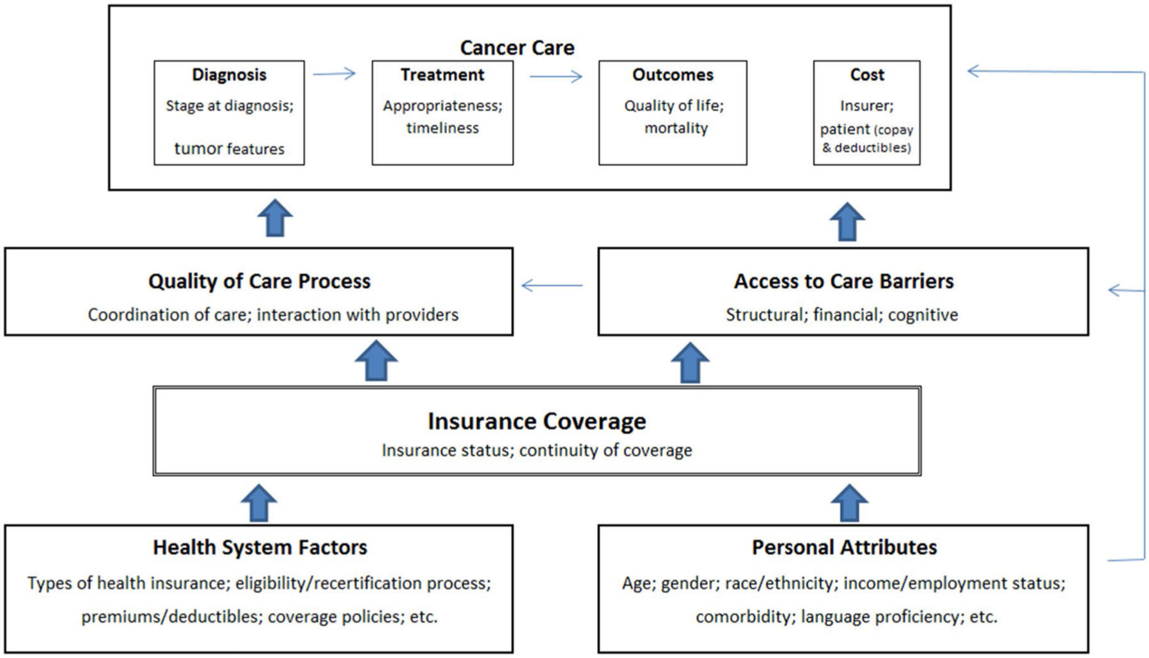

**Fig. 1.**

Conceptual model of access to quality cancer care. Figure depicts a model of cancer care, starting with personal and health system attributes, moving though insurance, and its effects on access and quality of caret and ending in outcomes

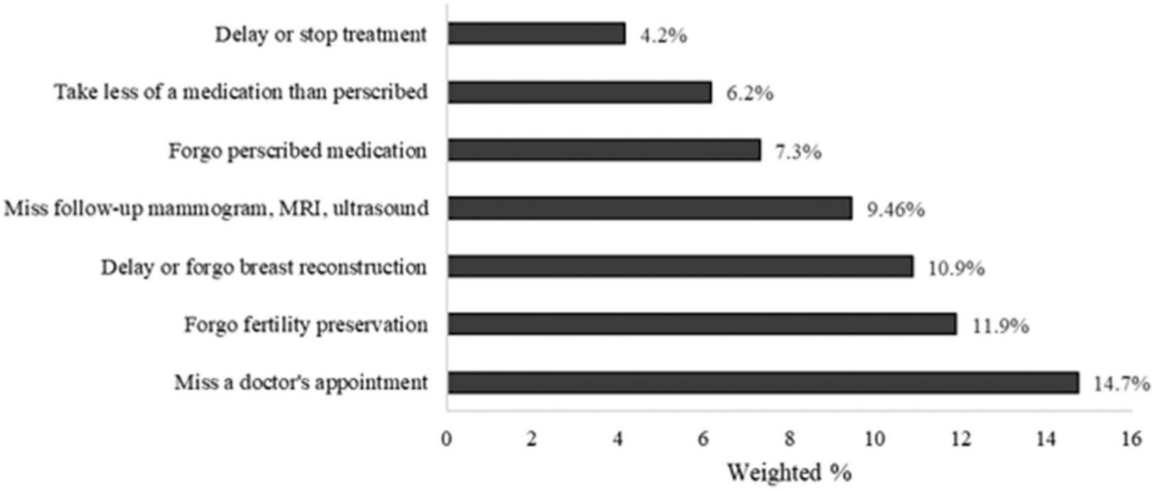

**Fig. 2.**

Because of your medical cost, did you have to… Figure displays the proportion of respondents who had to forgo certain treatments due to cost. The question posed was 'Because of your medical cost, did you have to: **a** delay or stop breast cancer treatment? **b** go without any medication prescribed? **c** take less than the fully prescribed amount of a prescription? **d** miss a doctor's appointment? **e** miss a follow-up mammogram, MRI, or ultrasound? **f** delay or did not receive breast reconstruction? **g** forgo fertility preservation?

## Table 1

Demographic and clinical characteristics

| Characteristic | No. *n* = 830 | Weighted % |
|---|---|---|
| *Age at diagnosis* | | |
| 18–34 years | 506 | 60.5 |
| 35–39 years | 324 | 39.5 |
| *Race/ethnicity* | | |
| White (non-Hispanic) | 487 | 48.1 |
| Black (non-Hispanic) | 111 | 17.9 |
| Hispanic | 153 | 23.9 |
| Asian/Pacific Islander (non-Hispanic) | 38 | 5.3 |
| Other (non-Hispanic) | 33 | 3.9 |
| Missing | 8 | 1.0 |
| *Marital status (at time of survey)* | | |
| Single | 106 | 13.5 |
| Married/with partner | 602 | 71.1 |
| No longer married | 95 | 12.0 |
| Missing | 27 | 3.4 |
| *Education (at time of survey)* | | |
| Graduate degree | 201 | 23.1 |
| Bachelor’s degree | 291 | 34.3 |
| Some college | 222 | 27.2 |
| High school or less | 101 | 13.6 |
| Missing | 15 | 1.9 |
| *Comorbid conditions (at time of survey)* | | |
| None | 184 | 22.3 |
| One condition | 169 | 20.2 |
| Two or more conditions | 477 | 57.5 |
| *Stage at diagnosis* | | |
| Stage 0 | 91 | 10.9 |
| Stage I | 180 | 20.6 |
| Stage II | 293 | 35.4 |
| Stage III | 173 | 21.4 |
| Stage IV | 53 | 6.9 |
| *Missing* | 40 | 4.9 |
| *Insurance type at diagnosis* | | |
| Private (employer based) | 573 | 67.2 |
| Self-insured | 63 | 7.3 |
| Medicaid or Medicare | 82 | 10.8 |
| Uninsured | 63 | 8.6 |
| Other | 38 | 4.8 |
| Missing | 11 | 1.5 |

| **Characteristic** | **No. *n* = 830** | **Weighted %** |
|---|---|---|
| *Employment status at diagnosis* | | |
| Employed | 620 | 73.4 |
| Unemployed | 200 | 25.3 |
| Missing | 10 | 1.3 |
| *State of diagnosis* | | |
| California | 268 | 32.7 |
| Florida | 246 | 29.7 |
| Georgia | 152 | 19.1 |
| North Carolina | 164 | 18.6 |

## Table 2

Cost of breast cancer care and impact on decision making

| | **No *n* = 830** | **Weighted %** |
|---|---|---|
| *Degree to which insurance covered treatment and other breast cancer care costs* | | |
| More than expected | 259 | 31.2 |
| Expected amount | 391 | 46.7 |
| Less than expected | 145 | 17.3 |
| Uninsured—not applicable | 15 | 2.0 |
| Missing | 20 | 2.8 |
| *Personal expenditures on treatment and other breast cancer care was* | | |
| More than expected | 395 | 47.4 |
| Expected amount | 272 | 32.3 |
| Less than expected | 144 | 17.5 |
| Missing | 19 | 2.8 |
| *Discussed treatment costs with care team* | | |
| Yes | 283 | 33.5 |
| No | 537 | 65.3 |
| Missing | 10 | 1.2 |
| *Considered cost in treatment course selection* | | |
| A great deal | 70 | 8.7 |
| Somewhat | 177 | 20.9 |
| Not at all | 571 | 68.7 |
| *Missing* | 12 | 1.7 |
| *How much of a problem was it to get the breast cancer care that you or a doctor believed was necessary?* | | |
| Not a problem | 561 | 67.7 |
| A small problem | 194 | 23.1 |
| A large problem | 66 | 8.2 |
| Missing | 9 | 1.0 |

## Table 3

Multivariable analysis of factors related to forgoing any care due to cost

| Covariate | Did not receive any care due to cost (31.8% of respondents | | |
|---|---|---|---|
| | **OR** | **95% CI** | ***P*** |
| *Age* | | | |
| 35–39 years (reference) | 1.00 | | |
| 18–34 years | 1.51 | 1.06–2.14 | 0.022 |
| *Race/ethnicity* | | | |
| White (non-Hispanic) (reference) | 1.00 | | |
| Black (non-Hispanic) | 1.40 | 0.85–2.32 | 0.189 |
| Hispanic | 1.00 | 0.63–1.60 | 0.997 |
| Asian/Pacific Islander (non-Hispanic) | 1.21 | 0.44–3.28 | 0.713 |
| Other (non-Hispanic) | 2.67 | 1.24–5.76 | 0.012 |
| *Marital status* | | | |
| Unmarried (reference) | 1.00 | | |
| Married/ with partner | 0.89 | 0.61–1.32 | 0.538 |
| *Educational level* | | | |
| Bachelor’s or graduate degree (reference) | 1.00 | | |
| Some college | 1.15 | 0.78–1.70 | 0.476 |
| High school degree or less | 1.27 | 0.70–2.30 | 0.426 |
| *Comorbid conditions* | | | |
| None (reference) | 1.00 | | |
| One condition | 2.25 | 1.27–4.00 | 0.005 |
| Two or more conditions | 3.00 | 1.84–4.92 | < 0.001 |
| *Stage at diagnosis* | | | |
| Stage 0, I (reference) | 1.00 | | |
| Stage II | 1.60 | 1.07–2.39 | 0.022 |
| Stage III, IV | 1.89 | 1.21–2.93 | 0.004 |
| *Insurance status at diagnosis* | | | |
| Private (employer based) | 1.00 | | |
| Self-insured | 2.04 | 1.11–3.75 | 0.022 |
| Medicaid or Medicare | 1.33 | 0.72–2.44 | 0.365 |
| Uninsured | 1.34 | 0.72–2.50 | 0.353 |
| Other | 0.43 | 0.12–1.56 | 0.198 |
| *Employment status at time of diagnosis* | | | |
| Employed (reference) | 1.00 | | |
| Unemployed | 0.88 | 0.56–1.40 | 0.593 |
| *State of diagnosis* | | | |
| North Carolina (reference) | 1.00 | | |
| California | 0.61 | 0.37–0.98 | 0.041 |
| Florida | 0.83 | 0.52–1.32 | 0.424 |
| Georgia | 0.97 | 0.57–1.65 | 0.908 |

*CI* confidence interval; *OR* odds ratio; *P* p-value