



Published in final edited form as:

*Breast Cancer Res Treat.* 2011 June ; 127(2): 521–529. doi:10.1007/s10549-010-1225-0.

## Out of pocket cost comparison between Caucasian and minority breast cancer survivors in the Breast Cancer Education Intervention (BCEI)

### **Maria Pisu,**

School of Medicine, Division of Preventive Medicine, University of Alabama at Birmingham, 1530 3rd Ave South, MT 636, Birmingham, AL 35294-4410, USA; Comprehensive Cancer Center, University of Alabama at Birmingham, Birmingham, AL, USA

### **Andres Azuero,**

Comprehensive Cancer Center, University of Alabama at Birmingham, Birmingham, AL, USA; School of Nursing, University of Alabama at Birmingham, Birmingham, AL, USA

### **Karen Meneses,**

Comprehensive Cancer Center, University of Alabama at Birmingham, Birmingham, AL, USA; School of Nursing, University of Alabama at Birmingham, Birmingham, AL, USA

### **Jeffrey Burkhardt, and**

School of Health Professions, University of Alabama at Birmingham, Birmingham, AL, USA

### **Patrick McNees**

Comprehensive Cancer Center, University of Alabama at Birmingham, Birmingham, AL, USA; School of Nursing, University of Alabama at Birmingham, Birmingham, AL, USA; School of Health Professions, University of Alabama at Birmingham, Birmingham, AL, USA

Maria Pisu: mpisu@uab.edu

## Abstract

The purpose of this article is to: (1) describe out of pocket (OOP) costs among minority and Caucasian participants in the BCEI, the Breast Cancer Education Intervention, a randomized clinical trial of psychoeducational quality of life interventions for breast cancer survivors (BCS); and (2) examine the OOP burden, as measured by the proportion of income spent OOP, between the two racial/ethnic groups. We examined baseline OOP costs reported by 261 early-stage I and II breast cancer survivors who participated in the BCEI trial. Data were collected using the Breast Cancer Finances Survey and the Breast Cancer Sociodemographic and Treatment Tool. OOP costs averaged \$316 per month since diagnosis. Direct medical costs were \$281, and direct non-medical were \$66. There were no significant differences in total OOP costs or direct medical and non-medical OOP costs between minority and Caucasian BCS. Minority BCS with incomes of \$40,000 or less spent a greater proportion of income in total OOP and direct medical OOP costs (31.4 and 27% for BCS with incomes  $\leq$ \$20,000; 19.5 and 18.8% for BCS with incomes \$20,001–40,000) compared to their Caucasian counterparts (12.6 and 9.2% for BCS with incomes  $\leq$ \$20,000; 8.7 and 8.2% for BCS with incomes \$20,001–40,000). OOP costs can be a considerable burden for breast cancer survivors representing as much as 31% of monthly income depending on BCS' income levels. Future studies can investigate how this burden affects the quality of life of breast cancer survivors, especially minorities.

---

Correspondence to: Maria Pisu, mpisu@uab.edu.

**Conflict of interest** None.

## Keywords

Breast cancer; Cancer survivors; Out of pocket costs; Economic burden

---

## Introduction

In 2010 more than 200,000 women and families will be affected by breast cancer [1] and the economic burden that accompanies this disease [2]. To date, the predominance of studies on the cost of breast cancer focuses on expenditures incurred by third party payers [3]. However, the costs to patients and families are considerable as well [4]. Out of pocket costs (OOP), i.e., expenditures not reimbursed by third party payers, are part of the economic burden of cancer survivorship. These costs are often hidden, rarely collected, and are not well understood. Only a few studies report on *medical direct OOP costs* of breast cancer patients, e.g., OOP expenses for co-payments for physicians' fees and hospital bills, or on *non-medical direct costs*, e.g., OOP costs for transportation to hospitals or doctors' offices, expenses for health maintenance activities such as special diet or clothing and expenditures for physical activities [4,5].

The burden of OOP costs may be particularly problematic given our current global economic climate especially for minority survivors. This group of women, who typically have lower socio-economic status [6], may be suffering the consequences of a higher economic burden compared to non-minority groups. In fact, poorer patients have been found to be disproportionately affected by the burden of out of pocket expenditures [7,8], especially those that are not avoidable such as those for doctor fees or the expense for transportation to doctors' offices [9]. Studies that report OOP costs incurred by minority breast cancer survivors are nearly non-existent.

In the (Breast Cancer Education Intervention) BCEI, a randomized trial of quality of life, psychoeducational support interventions, we collected OOP cost data from early-stage breast cancer survivors who were in the first year post primary treatment [10]. The purpose of this article is to: (1) describe OOP costs reported by participants in the BCEI; and to (2) compare economic burden, as measured by the proportion of income spent OOP, between two racial/ethnic groups of Caucasian and minority breast cancer survivors.

## Methods

We conducted a retrospective analysis of data collected at baseline from participants in the BCEI trial. The efficacy of this trial has been reported elsewhere [10]. Briefly, breast cancer survivors were recruited from a regional cancer center and private oncology offices in the Southeastern United States. Participants eligible for the study were: at least 21 years of age, diagnosed with histologically confirmed stage I–II breast cancer with no evidence of recurrent or metastatic disease, within 2 years since diagnosis, and a minimum 1 month time period since completion of surgery, radiation therapy, and/or chemotherapy. Participants may have been on hormonal therapy (i.e., aromatase inhibitor or tamoxifen) at study entry. The BCEI Principal Investigator received institutional review board approval to conduct the primary study.

## Measures

The BCEI measures examined several factors. Those most relevant to this secondary analysis include: (1) the Breast Cancer Treatment and Sociodemographic Data Tool; and (2) the Breast Cancer Finances Survey (BCFS). Baseline data were collected prior to randomization to the Experimental or Wait Control arm.

1. *Breast Cancer Treatment and Sociodemographic Data Tool* This tool consists of 32 items that document breast cancer treatment variables (i.e., surgery, radiation therapy, chemotherapy, hormonal, and anti-HER2 therapy) and sociodemographic characteristics (e.g., age, race, ethnicity, education, marital status, employment status, and family income).
2. *Breast Cancer Finances Survey (BCFS)* The BCFS is a self-report measure of 44 items of which 20 items are about general out of pocket costs. Respondents were asked to report any OOP expense they had from the time of diagnosis for insurance (e.g., health insurance, monthly premiums, and health benefits), medical care (e.g., hospital bills, doctor bills, and urgent care), medicines (e.g., medicine for cancer and other chronic diseases), alternative treatment and services (e.g., nutritional counseling), and other health care needs and services (e.g., wigs, prostheses, exercise, and help with home maintenance). This inventory was adapted from Given and colleagues [11].

### Data analysis

Frequencies of participants' sociodemographic and treatment characteristics were tabulated and then tested for differences between Caucasian and minority women using  $\chi^2$  or Fisher's exact tests as appropriate.

Costs were updated to 2008 US dollars using the consumer price index and expressed in monthly cost by dividing the reported amounts by the number of months since diagnosis. We examined the monthly OOP costs for each cost category, i.e., direct medical and direct non-medical, for survivors who reported non-zero costs. Further, we examined OOP costs reported by race/ethnicity. Tests of mean differences between Caucasian and minority women were conducted using Gamma regression models (i.e., generalized linear models with Gamma-distributed outcomes and logarithmic-link functions). The Gamma distribution was used because of the marked right-skewness in the observed distribution of the costs. For each OOP cost category a model was developed that had minority status as the primary explanatory variable of interest, and as covariates sociodemographic and treatment characteristics significantly different between Caucasian and minority women.

To examine the burden of OOP costs, we examined OOP costs as a proportion of reported income. Income was reported in four categories of less than \$20,000 to incomes greater than \$50,000. We used the middle value of the income category as the denominator, and for incomes >\$50,000 we used \$55,000. Tests of mean differences in proportion of income spent in OOP between Caucasian and minority women were conducted using Beta-regression models (generalized linear models with Beta-distributed outcomes and logit-link functions). The Beta distribution is a flexible statistical distribution restricted to the interval [0,1] and commonly used to model proportions. A model for the proportion of income spent in OOP was fitted with minority status and family income as primary explanatory variables of interest. Covariates were sociodemographic characteristics significantly different between Caucasian and minority women. Linear contrasts were used to test the mean differences in proportion spent in OOP between Caucasian and minority women at each family income level.

### Results

A total of 261 breast cancer survivors (BCS) participated in the BCEI. Table 1 compares demographic and treatment characteristics between Caucasian ( $n = 215$ ) and minority BCS ( $n = 46$ ). In terms of sociodemographic characteristics, significant differences were noted in rural residence, with 6.5% of minority BCS living in rural areas compared with 23.3% of

Caucasians ( $P = 0.01$ ). There was a significant difference in the stage of disease between the two groups of survivors with 43.5% of minority BCS having Stage I disease compared with 62.2% of Caucasian BCS, and 56.5% of minority BCS having stage II disease compared to 37.8% of Caucasian BCS ( $P = 0.02$ ). There were also significant differences in treatment received, with 69.6% of minority BCS having received chemotherapy compared with 50.7% of Caucasians ( $P = 0.02$ ). Moreover, 50% of minority BCS received both chemotherapy and radiation therapy compared to 28.4% of Caucasians, while 26.1% of minority BCS received radiation only compared to 39.5% of Caucasians ( $P = 0.036$ ).

### Out of pocket costs

Table 2 lists the direct medical and non-medical OOP monthly costs for BCEI participants. The mean total monthly direct OOP costs were \$316.1 (SD = \$411.5; median = \$206.3). Mean direct medical OOP costs for prescriptions, medical and hospital bills, over the counter medications, side effect management, etc. were \$280.7 (SD = \$398.4; median = \$177.3). Nearly 93% of BCS ( $n = 242$ ) had direct medical OOP costs; 87.0% incurred expenses for prescription medications, 73.2% had OOP costs for doctors' bills, 65.5% had OOP costs for hospital bills, and more than 42.0% reported OOP costs for over the counter medications. In addition, nearly 40% reported expenditures for side effect management such as prostheses or wigs with a mean OOP cost of \$25.6 (SD = \$20.0; median \$20.7), and 32.2% had OOP expenses for medical supplies for an average \$18.1 per month (SD = \$25.6; median \$9.6).

Nearly 60% of breast cancer survivors reported direct non-medical OOP costs. The mean direct non-medical OOP costs was \$65.7 per month (SD = \$96.9; median = \$30.3). The most frequent expenses reported were for travel to the hospital or doctor (42.9%), and physical therapy and exercise (14.9%). The average amounts for these expenses were about \$43.9 (SD = \$58.2; median = \$23.8) and \$26.1 (SD = \$41.7; median = \$13.6), respectively. About 9% of BCS reported a mean of \$60.4 for OOP cleaning expenses and a mean of \$52.1 for home maintenance. In addition, 9.2% reported a mean monthly increase in insurance premiums of about \$11.2 (SD = 11.7; median = \$6.7).

### Comparison of OOP costs based on minority status

Table 3 lists the monthly OOP costs by minority status. The mean OOP costs for Caucasian BCS was \$297.3 (SD = \$296.8; median = \$204.8) of which \$261.3 (SD = \$275.9; median = \$167.4) were spent on direct medical care. Minority BCS spent \$405.6 per month on average (SD = \$746.9; median = \$217.2) of which \$375.9 was spent on direct medical care (SD = \$751.4; median = \$203.6). Similar proportions of Caucasian and minority women reported OOP expenditures for hospital and doctor bills, prescriptions, over the counter drugs, medical supplies, and alternative treatments. About 11% of minority women and 6% of Caucasian women reported OOP expenses for emergency care visits; however, minority BCS spent on average \$44 (SD = \$22.4; median = \$44.8) and Caucasians \$12.4 (SD = \$9.8; median = \$8.8). In analyses adjusted for three factors (stage of disease, rural residence and chemotherapy), the difference in expenditures between Caucasian and minority BCS was significant ( $P = 0.003$ , Table 4). Moreover, 50.0% of minority BCS reported expenses for side effect management (e.g., wigs, prostheses) compared to 37.7% of Caucasian BCS, but the mean amount spent was similar between the two groups (\$23.7 [SD = 25.4; median = 15.8] for minority BCS versus \$26.2 [SD = 18.3; median = 21.6] for Caucasians) ( $P = 0.649$ , Table 4). Minority BCS spent less on individual counseling and none reported OOP expenses for family counseling. The difference in expenditures between Caucasian and minority BCS for individual counseling was significant ( $P = 0.001$ ) (Table 4). However, for some of these OOP costs, the models were based on a small number of women; therefore,

results should be interpreted with caution. Overall, there were no significant differences in total direct medical costs between the two groups.

Fifty-eight percent of Caucasian BCS reported a mean of \$65.5 spent on non-medical direct OOP costs per month (SD = \$96.6; median = \$34.9) compared with 65.2% of minority BCS who reported a mean of \$66.8 per month (SD = \$100.1; median = \$25) ( $P = 0.76$ ). Similar proportions of Caucasian and minority BCS reported expenditures for travel to obtain medical care, cleaning, and home maintenance. Physical therapy or exercise expenses were reported by 21.7% of minority BCS and 13.5% of Caucasians. However, the average amount spent by minority BCS was \$12.3 (SD = \$11.2; median = \$8.4), and was lower compared to \$30.8 spent by Caucasian BCS (SD = 47.1; median = \$20.4,  $P = 0.005$ ). In addition, 10.9% of minority BCS and 8.8% of Caucasians reported increase in health insurance premiums. Minority BCS reported a mean increase of \$5.7 per month (SD = 3.8; median = \$6.8) compared to Caucasian BCS who reported a mean increase of \$12.6 (SD = \$12.6; median = \$6.5). In the adjusted analyses, there were significant differences between the Caucasian and minority women with Caucasians reporting higher OOP costs for physical therapy and exercise OOP expenses ( $P = 0.005$ ) and insurance premium increases ( $P = 0.004$ ). In these cases, the models were based on a small number of women and results should be viewed with caution.

Table 4 reports the effects of other covariates on OOP costs. Urban residence had a significant effect on some of the direct non-medical costs such as: (i) travel costs, with urban BCS reporting on average about 53% ( $e^{-0.64} = 0.53$ ) of the cost incurred by rural BCS; (ii) cleaning costs, with urban BCS reporting on average 3.5 times the cost incurred by rural BCS; and (iii) insurance premium increases, with urban BCS reporting on average 5.3 times the cost incurred by rural BCS. Stage of disease and receipt of chemotherapy had significant effects on both direct medical and non-medical costs (Table 4). Stage I BCS spent on average 22% of the cost incurred by stage II BCS on ER visits and 31% of the cost incurred by stage II BCS on insurance premium increases. They also spent 4.9 times the cost incurred by stage II BCS on individual counseling, 2.3 times the cost incurred by stage II BCS on physical therapy and exercise, 2.5 times the cost incurred by stage II BCS on cleaning. Furthermore, BCS who received chemotherapy spent on average 1.5 times more in direct medical and total costs compared to BCS who did not receive chemotherapy. In particular, they spent on average 1.5 times the cost incurred by those not receiving chemo on prescription medicines, 2.2 times the cost of physical therapy and exercise, and 2.0 times the cost of cleaning.

### OOP Costs as a proportion of reported income

Table 5 shows that survivors with lower annual family incomes spent a higher proportion of their income on OOP costs. Minority BCS with incomes of \$20,000 or less spent 27% of their income on direct medical OOP costs, 6.3% on direct non-medical OOP costs, and 31.4% on total OOP costs compared with 9.2, 4.8, and 12.6% of Caucasian BCS, respectively. Differences in the burden of direct medical and total OOP costs for this income group were statistically significant after adjusting for rural/urban residence, stage of disease and receipt of chemotherapy ( $P = 0.001$ ) (Table 6). Among BCS with incomes between \$20,001 and 40,000, minority BCS spent 18.8% of their income on direct medical costs, 3.0% on direct non-medical costs, and 19.5% on total OOP costs compared to 8.2, 1.4, and 8.7 of Caucasians, respectively (Table 5). These differences in burden of direct medical and total OOP costs were statistically significant ( $P = 0.001$ ) (Table 6). No significant differences were found for the proportion of income spent on OOP costs between minority and Caucasian BCS in higher income groups (Table 6). In addition, the receipt of chemotherapy significantly affected the proportion of income spent on total and medical direct OOP costs: women who did not receive chemotherapy spent significantly smaller



proportions of their incomes on direct medical and total direct OOP costs than women who received this treatment (Table 6).

## Discussion

The BCEI is one of the few studies to describe OOP costs incurred by breast cancer survivors after diagnosis. Medical direct costs averaged \$281 per month and were primarily spent on prescription drugs and doctors' visits. More than 65% of survivors paid OOP costs for hospital bills. Non-medical costs amounted to another \$65 per month, mostly for travel to doctors' visits and physical therapy or exercise. Overall women spent an average of \$316 per month on total OOP costs since diagnosis.

While few studies reported OOP costs for breast cancer survivors, these costs have been shown to constitute a substantial economic burden even for those who have completed primary treatment [4]. Total direct medical OOP costs have been reported to be between \$200 and 1,180 per month [4]. The OOP costs of \$281 for participants in the BCEI trial fall in this range. However, compared to other studies, our OOP costs did not include costs of care during active treatment such as expenses for second opinion visits, supplements, nursing care, speech therapy, special equipment, and/or experimental treatment [7]. If these were included, we may have found higher OOP costs for BCEI participants. In addition to direct medical costs, BCEI participants spent about \$65 per month in direct non-medical costs, mainly for travel to doctors' visits. These costs are lower than similar costs reported in other studies which were estimated to be more than \$130 in 2008 dollars [4]. However, as for direct OOP costs, these may be higher as we did not collect information on some OOP non-medical costs such as restaurant meals, telephone calls, laundry services, and hotel stays that were instead included in previous studies [7,12].

Overall, OOP costs did not significantly differ between Caucasian and minority survivors. In part, these results may be related to the small number of minority BCS in the BCEI. Yet, minority BCS spent significantly more on emergency care visits, and less on individual counseling, reported no OOP costs for family counseling, and spent less on physical therapy or exercise. A possible explanation is that minority BCS may have less access to these types of services. Moreover, counseling or exercise may be one of those expenses that survivors accept as avoidable [9] or avoided because "not in the budget" [13] as they may have had fewer funds available to pay for psychosocial support services. To the extent that these services contribute to improved physical and emotional well being of BCS, minority BCS may have been faced with decisions to cut services that would improve their quality of life during survivorship. Furthermore, while minority women were more likely to reside in urban areas than Caucasian women, they were as likely to incur travel costs and spent similar amounts on average. This may indicate the existence of yet another obstacle to obtain medical care faced by disadvantaged survivors.

Despite finding no differences in OOP costs between minority and Caucasian women, we found that the burden of OOP costs, as measured by the proportion of income spent OOP, was higher for minority BCS. Of particular concern is that the burden was significantly higher for minority BCS with incomes of \$40,000 or less. Similarly, other investigators had reported that low income cancer survivors bear a disproportionate share of OOP costs [7,8]. However, they had not examined the differences in this burden between minority and Caucasian survivors. Our findings highlight the critical importance of further defining OOP costs and economic burden in cancer survivorship over time, and of the need to examine how economic burden contributes to cancer disparities.

As reported on the costs of breast cancer to health care payers, adjuvant chemotherapy and more advanced disease add to the economic burden of breast cancer survivors [3]. Women who did not receive chemotherapy spent less OOP overall and as a proportion of income. In particular, they spent less on prescription drugs, physical therapy or exercise, and cleaning compared to women who received chemotherapy. This may reflect better quality of life in women who do not need chemotherapy with fewer side effects that require physical therapy and better ability to perform everyday activities. Similarly, women with more severe breast cancer did not spend more OOP than women with less severe disease overall, but they spent less on physical therapy/exercise and cleaning and more on ER visits and insurance premium increases. Finally, rural BCS did not spend more OOP overall than women living in urban areas, except for a few OOP items such as those for travel to the hospital or doctor's offices.

This study has some limitations. First, the sample of minority women was small, and therefore, there were cost categories, such as counseling and child care, for which very small numbers of participants, if any, reported having incurred these costs. These small numbers may result in unstable statistical test results. However, this represents one of the largest groups of minority BCS included in studies of OOP costs [7,12]. In addition, given the limited number, we were not able to analyze OOP costs separately for women of specific minority groups such as African Americans or Hispanics. Second, the OOP costs were self-reported by BCS and were not compared to expenditure records or other similar documents. Therefore, reported dollar amounts may have been the best recollection of these costs by the participant. However, we do find that the total OOP amount falls in the range of OOP costs previously reported in the literature. In addition, our instrument required that BCS recall costs incurred since diagnosis: therefore, participants further away from diagnosis may have had more difficulties recollecting these costs. However, only about 6% of participants, and more importantly, similar proportions of Caucasian and minority women, were assessed more than a year past diagnosis.

## Conclusion

In summary, OOP costs in the year post diagnosis are a substantial burden for breast cancer survivors: we estimated that they represent 7% or more of BCS' monthly income and up to 31% for minority BCS in the lowest reported income bracket. It is of particular concern that minority BCS with lower incomes appear to be disproportionately burdened by these costs. Studies involving a larger representation of minority survivors are necessary not only to further document the burden of OOP costs, but also to understand whether these costs affect decisions on what services to use and, ultimately, quality of life of BCS in general, and minority BCS in particular.

## Acknowledgments

Grant support from the National Institute of Nursing Research and the Office of Cancer Survivorship at the National Cancer Institute (#5R01NR5332; PI: Meneses), USA.

## References

1. American Cancer Society. Cancer facts and figures 2010. American Cancer Society; Atlanta: 2010.
2. Hewitt, MS.; Greenfield, S.; Stovall, E., editors. From cancer patient to cancer survivor: lost in transition. The National Academies Press; Washington, DC: 2005.
3. Campbell JD, Ramsey SD. The costs of treating breast cancer in the US: a synthesis of published evidence. *Pharmacoeconomics*. 2009; 27(3):199–209. [PubMed: 19354340]
4. Pisu M, Azuero A, McNees P, Burkhardt J, Benz R, Meneses K. The out of pocket cost of breast cancer survivors: a review. *J Cancer Surviv*. 2010; 4(3):202–209. [PubMed: 20401542]

5. Brown, ML.; Yabroff, KR. Economic impact of cancer in the United States. In: Schottenfeld, D.; Fraumeni, JF., editors. Cancer epidemiology and prevention. 3rd. Oxford University Press; New York: 2006.
6. DeNavas-Walt, C.; Proctor, BD.; Smith, JS. Income, poverty, and health insurance coverage in the United States:2008 current population reports. US Census Bureau; Washington, DC: 2009. p. 60-236.
7. Arozullah AM, Calhoun EA, Wolf M, Finley DK, Fitzner KA, Heckinger EA, Gorby NS, Schumock GT, Bennett CL. The financial burden of cancer: estimates from a study of insured women with breast cancer. *J Support Oncol*. 2004; 2(3):271–278. [PubMed: 15328826]
8. Langa KM, Fendrick AM, Chernew ME, Kabeto MU, Paisley KL, Hayman JA. Out-of-pocket health-care expenditures among older Americans with cancer. *Value Health*. 2004; 7(2):186–194. [PubMed: 15164808]
9. Lauzier S, Maunsell E, De Koninck M, Drolet M, Hebert-Croteau N, Robert J. Conceptualization and sources of costs from breast cancer: findings from patient and caregiver focus groups. *Psychooncology*. 2005; 14(5):351–360. [PubMed: 15386763]
10. Meneses KD, McNees P, Loerzel VW, Su X, Zhang Y, Hassey LA. Transition from treatment to survivorship: effects of a psychoeducational intervention on quality of life in breast cancer survivors. *Oncol Nurs Forum*. 2007; 34(5):1007–1016. [PubMed: 17878129]
11. Given BA, Given CW, Stommel M. Family and out-of-pocket costs for women with breast cancer. *Cancer Pract*. 1994; 2(3):187–193. [PubMed: 8055022]
12. Moore KA. Breast cancer patients' out-of-pocket expenses. *Cancer Nurs*. 1999; 22(5):389–396. [PubMed: 10526432]
13. Sherwood PR, Donovan HS, Rosenzweig M, Hamilton R, Bender CM. A house of cards: the impact of treatment costs on women with breast and ovarian cancer. *Cancer Nurs*. 2008; 31(6): 470–477. [PubMed: 18987515]



**Table 1**  
**Sociodemographic and treatment characteristics of women participating in the BCEEI trial (n = 261)**

Characteristic	All women		Caucasian women (n = 215) (%)	Minority women (n = 46) (%)	P*
	Number	(%)			
Stage of disease at diagnosis					
I	153	58.9	62.2	43.5	0.020
II	107	41.1	37.8	56.5	
Time since diagnosis					
12 months or less	244	94.2	94.4	93.5	0.735
12–24 months	15	5.8	5.6	6.5	
Age groups					
28–45	64	24.5	23.2	30.4	0.558
46–64	147	59.0	59.1	58.7	
65–83	50	16.5	17.7	10.9	
Marital status					
Never married or widowed	34	13.0	13.0	13.0	0.205
Married or living w/partner	178	68.2	70.2	58.7	
Separated/divorced	49	16.9	16.8	28.3	
Rural residence	53	20.3	23.3	6.5	0.010
Employment status					
Full-time	140	53.6	53.0	56.5	0.595
Part-time	24	9.2	8.4	13.0	
Retired	61	23.4	25.1	15.2	
Homemaker	22	8.4	8.4	8.7	
Unemployed or student	6	2.3	1.8	4.4	
On disability	8	3.1	3.3	2.2	
Family income					
≤\$20,000	30	11.5	11.2	13.0	0.187
\$20,001–40,000	53	20.3	17.7	32.6	
\$40,001–50,000	33	12.6	13.0	10.9	
≥\$50,001	125	47.9	50.7	34.8	

Characteristic	All women		Caucasian women (n = 215) (%)		Minority women (n = 46) (%)		P*
	Number	(%)					
Declined to answer	20	7.7		7.4		8.7	
Surgery received							
Lumpectomy	158	60.5		60.0		63.0	0.866
Mastectomy	75	28.8		28.8		28.3	
Bilateral mastectomy	28	10.7		11.2		8.7	
Chemotherapy	141	54.0		50.7		69.6	0.020
Radiation	181	69.3		67.9		76.1	0.275
Hormonal therapy <sup>a</sup>	197	75.5		76.7		69.6	0.313
Treatment mix							
Surgery only	23	8.8		9.8		4.4	0.036
Surgery, chemotherapy	57	21.8		22.3		19.6	
Surgery, radiation	97	37.2		39.5		26.1	
Surgery, chemo, radiation	84	32.2		28.4		50.0	

\* Fisher's exact test or  $\chi^2$  test, as appropriate

<sup>a</sup> On hormonal treatment at the time the data were collected

**Table 2**  
**Descriptive statistics for OOP costs in 2008 dollars reported by women participating in the BCEI trial (n = 261)**

Cost category	Women with cost		Monthly OOP costs (\$)			
	Number	(%)	Mean	SD	Median	Interquartile Range (Q1-3)
Direct medical OOP cost	242	92.7	280.7	398.4	177.3	84.6-374
Prescription medicines	227	87.0	46.0	70.9	27.4	11.6-51.7
Doctor bills	191	73.2	97.0	144.2	54.8	32.2-112
Hospital bills	171	65.5	183.2	280.5	108.2	49.2-224.1
OTC medicines	110	42.1	8.6	9.2	5.9	3-10.8
Side effect management (wigs, prostheses)	104	39.8	25.6	20.0	20.7	13.1-31.2
Medical supplies	84	32.2	18.1	25.6	9.6	4.1-19.6
Alternative treatments	35	13.4	28.4	32.8	16.4	8.2-35.3
ER visits	17	6.5	21.7	20.3	13.0	7.9-32.4
Counseling						
Individual (genetic, nutritional)	16	6.1	68.0	146.3	9.7	3.9-38
Family	5	1.9	11.6	7.8	10.5	7.4-15.8
Direct non-medical OOP cost	155	59.4	65.7	96.9	30.3	12.7-70.8
Travel to hospital or doctor	112	42.9	43.9	58.2	23.8	11.1-42.8
Physical therapy, exercise	39	14.9	26.1	41.7	13.6	7.8-29
Cleaning	25	9.6	60.4	60.4	39.0	15.6-65.1
Insurance premium increases	24	9.2	11.2	11.7	6.7	3.4-14.1
Home maintenance	23	8.8	52.1	42.8	35.4	13.5-76
Child care	3	1.1	73.9	16.1	76.6	56.7-88.4
Other	11	4.2	95.5	126.7	45.9	24-152.1
Total direct OOP cost	248	95.0	316.1	411.5	206.3	104.8-410.3

**Table 3**  
**Descriptive statistics of OOP costs in 2008 dollars for Caucasian (n = 215) and minority women (n = 46) participating in the BCEI trial**

Cost category	Women reporting cost		Monthly OOP costs (\$)						
			Caucasian women			Minority women			
	Caucasian	Minority	P*	Mean	SD	Median	Mean	SD	Median
Direct medical cost	93.5	89.1	0.345	261.3	275.9	167.4	375.9	751.4	203.6
Prescription medicines	87.4	84.8	0.633	47.0	76.7	26.4	41.0	29.8	34.0
Doctor bills	72.6	76.1	0.610	87.4	94.5	55.6	139.6	270.5	50.3
Hospital bills	65.1	67.4	0.767	170.4	179.3	109.2	241.3	541.0	98.2
OTC medicines	40.9	47.8	0.392	9.2	10.0	5.9	6.4	4.0	5.9
Side effect management	37.7	50.0	0.124	26.2	18.3	21.6	23.7	25.4	15.8
Medical supplies	31.6	34.8	0.679	17.5	25.4	8.9	20.4	27.1	13.0
Alternative treatments	13.5	13.0	0.936	27.5	28.7	19.4	32.7	51.8	10.7
ER visits	5.6	10.9	0.192	12.4	9.8	8.8	44.0	22.4	44.8
Counseling									
Individual (genetic, nutrition)	6.0	6.5	1.000	82.4	159.9	15.8	5.5	3.4	4.3
Family	2.3	0.0	0.590	11.6	7.8	10.5	–	–	–
Direct non-medical cost	58.1	65.2	0.375	65.5	96.6	34.9	66.8	100.1	25.0
Travel to hospital or doctor	43.3	41.3	0.808	44.9	59.8	24.4	38.9	50.6	22.9
Physical therapy, exercise	13.5	21.7	0.172	30.8	47.1	20.4	12.3	11.2	8.4
Home maintenance	8.4	10.9	0.570	54.1	45.6	40.7	44.9	33.7	35.3
Cleaning	9.8	8.7	1.000	61.5	59.8	44.2	54.4	72.8	20.5
Insurance premium increases	8.8	10.9	0.586	12.6	12.6	6.5	5.7	3.8	6.8
Child care	1.4	0.0	1.000	73.9	16.1	76.6	–	–	–
Other	3.7	6.5	0.416	47.7	55.7	27.0	223.1	189.1	152.1
Total direct cost	95.3	93.5	0.707	297.3	296.8	204.8	405.6	746.9	217.2

\* Fisher's exact test or  $\chi^2$  test, as appropriate

**Table 4**  
**Results from Gamma regression models with log-links for mean OOP costs for women participating in the BCEI trial**

Cost category	Parameter estimate (SE) <sup>a</sup>				
	Intercept	Minority versus Caucasian	Urban versus rural residence	Stage I versus stage II breast cancer	No chemotherapy versus chemotherapy
Direct medical cost	5.974 (0.171)*	0.322 (0.309)	-0.308 (0.175)	-0.012 (0.172)	-0.417 (0.167)*
Prescription medicines	4.341 (0.228)*	-0.224 (0.174)	-0.287 (0.227)	-0.222 (0.188)	-0.399 (0.200)*
Doctor bills	4.866 (0.183)*	0.447 (0.326)	-0.313 (0.195)	-0.098 (0.193)	-0.287 (0.192)
Hospital bills	5.243 (0.192)*	0.426 (0.421)	-0.189 (0.205)	-0.110 (0.224)	0.217 (0.221)
OTC medicines	2.107 (0.227)*	-0.372 (0.194)	0.117 (0.247)	0.096 (0.218)	-0.068 (0.230)
Side effect management	3.237 (0.155)*	-0.107 (0.234)	0.086 (0.177)	-0.001 (0.157)	-0.452 (0.258)
Medical supplies	3.033 (0.363)*	-0.033 (0.385)	0.080 (0.411)	-0.666 (0.362)	0.300 (0.371)
Alternative treatments	3.135 (0.296)*	0.218 (0.617)	0.672 (0.383)	-0.535 (0.357)	-0.389 (0.338)
ER visits	2.847 (0.401)*	1.155 (0.305)*	-0.181 (0.481)	-1.473 (0.352)*	0.533 (0.373)
Counseling					
Individual (genetic, nutritional)	3.700 (0.787)*	-2.714 (0.645)*	-0.504 (0.731)	1.604 (0.600)*	-1.196 (0.845)
Family <sup>b</sup>	-	-	-	-	-
Direct non-medical cost	4.166 (0.281)*	0.099 (0.327)	-0.182 (0.293)	0.357 (0.265)	-0.149 (0.277)
Travel to hospital or doctor	3.907 (0.278)*	-0.041 (0.259)	-0.640 (0.285)*	0.258 (0.260)	0.522 (0.291)
Physical therapy, exercise	2.663 (0.415)*	-0.928 (0.309)*	0.631 (0.437)	0.821 (0.317)*	-0.798 (0.347)*
Home maintenance	3.764 (0.475)*	-0.171 (0.395)	-0.198 (0.495)	0.407 (0.414)	0.293 (0.421)
Cleaning	2.945 (0.292)*	-0.373 (0.646)	1.258 (0.321)*	0.908 (0.315)*	-0.679 (0.324)*
Insurance premium increases	1.209 (0.648)	-1.262 (0.385)*	1.683 (0.693)*	-1.147 (0.496)*	0.336 (0.408)
Child care <sup>b</sup>	-	-	-	-	-
Other	3.254 (0.652)*	1.241 (0.703)	1.020 (0.847)	0.214 (0.942)	-0.878 (0.906)
Total direct cost	6.094 (0.161)*	0.281 (0.277)	-0.301 (0.166)	-0.003 (0.163)	-0.421 (0.159)*

<sup>a</sup>Model predicts the natural logarithm of the mean OOP cost

<sup>b</sup>No minority participants reported cost,

\*  $P < 0.05$



**Table 5**  
**Descriptive statistics for OOP cost as proportion of income among women who participated in the BCEI trial by reported income (*n* = 216)**

Average proportion of income (%) spent OOP on									
Family income	Direct medical costs			Direct non-medical costs			Total direct OOP costs		
	All women	Caucasian women	Minority women	All women	Caucasian women	Minority women	All women	Caucasian women	Minority women
<\$20,000	12.5	9.2	27.0	5.2	4.8	6.3	16.1	12.6	31.4
\$20,001–40,000	10.8	8.2	18.8	1.9	1.4	3.0	11.5	8.7	19.5
\$40,001–50,000	6.4	6.5	5.7	2.2	1.9	3.7	7.9	7.7	8.7
≥\$50,001	6.9	6.9	6.9	1.5	1.6	0.9	7.8	7.8	7.5

**Table 6**  
**Results from beta-regression models with logit-links for mean OOP costs as proportion of income for participants of the BCEI trial**

Predictor	Parameter	Model Estimates (SE) <sup>a</sup>		
		Direct medical costs	Direct non-medical costs	Total direct OOP costs
Intercept	Intercept	-1.998 (0.160) *	-3.808 (0.185) *	-1.915 (0.152) *
Minority status	Minority versus Caucasian	0.009 (0.248)	-0.124 (0.312)	-0.017 (0.246)
Income	≤\$20,000 vs. > \$50,000	0.198 (0.219)	0.873 (0.246) *	0.484 (0.214) *
	\$20,001–40,000 vs. > \$50,000	-0.025 (0.177)	0.191 (0.224)	-0.038 (0.174)
	\$40,001–50,000 vs. > \$50,000	0.010 (0.197)	0.279 (0.232)	0.084 (0.194)
Income*Race	≤\$20,000; minority	1.280 (0.448) *	0.103 (0.524)	1.209 (0.439) *
	\$20,001–40,000; minority	0.893 (0.370) *	0.528 (0.442)	0.881 (0.364) *
	\$40,001–50,000; minority	-0.019 (0.503)	-0.130 (0.576)	0.027 (0.496)
Rural/urban residence	Urban versus rural residence	-0.144 (0.148)	-0.342 (0.174)	-0.128 (0.146)
Stage	Stage I versus stage II disease	-0.030 (0.137)	0.204 (0.159)	-0.040 (0.136)
Chemotherapy	None versus chemotherapy received	-0.359 (0.143) *	-0.250 (0.183)	-0.413 (0.144) *

\*  $P < 0.05$

<sup>a</sup>Model predicts the logit of the mean proportion, i.e.,  $\text{Ln}(p/(1-p))$