

Long-Term Financial Burden of Breast Cancer: Experiences of a Diverse Cohort of Survivors Identified Through Population-Based Registries

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ABSTRACT

Purpose

To evaluate the financial experiences of a racially and ethnically diverse cohort of long-term breast cancer survivors (17% African American, 40% Latina) identified through population-based registries.

Methods

Longitudinal study of women diagnosed with nonmetastatic breast cancer in 2005 to 2007 and reported to the SEER registries of metropolitan Los Angeles and Detroit. We surveyed 3,133 women approximately 9 months after diagnosis and 4 years later. Multivariable models evaluated correlates of self-reported decline in financial status attributed to breast cancer and of experiencing at least one type of privation (economically motivated treatment nonadherence and broader hardships related to medical expenses).

Results

Among 1,502 patients responding to both surveys, median out-of-pocket expenses were \leq \$2,000; 17% of respondents reported spending $>$ \$5,000; 12% reported having medical debt 4 years postdiagnosis. Debt varied significantly by race: 9% of whites, 15% of blacks, 17% of English-speaking Latinas, and 10% of Spanish-speaking Latinas reported debt ($P = .03$). Overall, 25% of women experienced financial decline at least partly attributed to breast cancer; Spanish-speaking Latinas had significantly increased odds of this decline relative to whites (odds ratio [OR], 2.76; $P = .006$). At least one privation was experienced by 18% of the sample; blacks (OR, 2.6; $P < .001$) and English-speaking Latinas (OR, 2.2; $P = .02$) were significantly more likely to have experienced privation than whites.

Conclusion

Racial and ethnic minority patients appear most vulnerable to privations and financial decline attributable to breast cancer, even after adjustment for income, education, and employment. These findings should motivate efforts to control costs and ensure communication between patients and providers regarding financial distress, particularly for vulnerable subgroups.

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INTRODUCTION

Considerable attention has focused on the financial burden of medical care,^{1,2} and experts have advocated for further research to investigate both the objective financial cost of cancer care and the subjective experiences of patients relating to these costs.³ Patients increasingly bear some of the cost of treatment through rising insurance premiums, deductibles, and copayments,⁴⁻⁶ and patients with cancer in particular have been shown to face higher out-of-pocket expenses than patients with other chronic conditions.^{7,8} Patients with cancer also face challenges in maintaining employment-related income to pay for these costs.⁹⁻¹²

Given the potential for both substantial expenses and challenges to maintaining income, patients with cancer may be particularly vulnerable to financial distress after diagnosis and treatment. Indeed, patients with cancer are more than twice as likely to file for bankruptcy as others,¹³ but less is known about how patients with cancer finance expenses or the privations they suffer as a result.¹⁴ In a population-based study of colon cancer survivors, 38% reported accruing debt, selling or refinancing their home, borrowing from friends or family, or experiencing \geq 20% income decline.¹⁵ Further research is necessary to define the financial burden of care for other types of cancer and to identify which patients are most vulnerable.

We evaluated the financial experiences of a diverse cohort of breast cancer survivors identified through population-based registries and how they varied by race/ethnicity. We specifically investigated self-reported out-of-pocket medical expenses, how they financed these expenses, their perceptions of their financial status, and the privations they experienced in the currently challenging broader economic environment. We also described these breast cancer survivors' experiences with employment after diagnosis and treatment. Finally, we evaluated whether certain racial/ethnic subgroups of long-term breast cancer survivors were more vulnerable to financial distress.

METHODS

Study Sample

We conducted a longitudinal cohort study of women diagnosed with breast cancer in metropolitan Los Angeles and Detroit. Patients age 20 to 79 years diagnosed with stage 0 to III breast cancer between June 2005 and February 2007, as reported to the National Cancer Institute's SEER population-based program registries in those regions, were eligible for sample selection.

Patients were excluded if they had stage IV breast cancer or could not complete a questionnaire in English or Spanish. Asian women in Los Angeles were excluded because of enrollment in other studies. Latina (in Los Angeles) and black (in both Los Angeles and Detroit) patients were oversampled to ensure sufficient minority representation.

Questionnaire Design and Content

Questionnaires were based on existing literature, measures previously developed to assess relevant constructs, and theoretical models. For the items relating to financial experiences, we adapted questions previously utilized by the Consumer Bankruptcy Project¹⁶; for items relating to employment and insurance experiences, we adapted questions from surveys conducted by the Bureau of Labor Statistics in the general population, and items previously developed by labor economists for use in patients with cancer.^{17,18} We utilized standard techniques of content validation,¹⁹ including systematic review by design experts²⁰⁻²² and pretesting with 40 patients in three waves, including 12 detailed cognitive interviews.^{23,24}

Data Collection

After institutional review board approval, patients were identified via rapid case ascertainment and surveyed a mean of 9 months after diagnosis, and again approximately 4 years later. To encourage response, we provided a \$10 cash incentive and used a modified Dillman method.²⁵ All materials were sent in English and Spanish to those with Spanish surnames.²⁶ The response rate to the baseline survey was 73%, and the response rate to the follow-up survey was 68%. Survey responses were combined into a single data set, into which clinical data from SEER were merged. More details regarding the flow of patients into the sample are provided in Appendix Fig A1, online only.

Measures

We included several measures of financial impact in the follow-up survey. First, we measured patients' perceptions of whether, since diagnosis, they were worse off financially (financial decline). Among those perceiving financial decline, we asked whether this was due to breast cancer. We dichotomized responses for analysis (a little bit, somewhat, quite a bit, or very much versus not at all). Those who indicated they were worse off because of breast cancer (a little bit, somewhat, quite a bit, or very much) were considered to have had financial decline attributed at least partly to breast cancer.

We also asked how much the respondent paid in total for out-of-pocket medical expenses related to breast cancer, including copayments, hospital bills, and medication costs, with categorical response options. We then asked how they paid for out-of-pocket expenses and asked whether survivors currently had debt from their breast cancer treatments.

We evaluated privations related to breast cancer by using two sets of items in the follow-up survey. First, we evaluated economically motivated

treatment nonadherence by asking whether in the past 12 months survivors had gone without medication, taken less than the fully prescribed amount of a medication, missed a doctor's appointment, or missed a mammogram because of cost. Second, we evaluated broader hardships related to the patient's medical expenses by asking whether, since breast cancer diagnosis, she or anyone in her household had gone without health insurance, had utilities turned off because of unpaid bills, or had to move out of their home because of the respondent's own personal medical expenses.

We also inquired regarding employment and insurance status in the follow-up survey, including whether, since diagnosis, women perceived they were worse off, and if so, if this was due to breast cancer. The follow-up survey inquired whether survivors had worked for pay since diagnosis. Among those who did, we asked how important it had been to avoid changing jobs because of worry about losing health insurance, to keep working to keep health insurance, or to get a new job in order to get health insurance (dichotomized for analysis as at least a little important versus not at all important). Among those working at any time since diagnosis, we asked whether they would look for a new job if they could be assured of comparable benefits, had increased work hours to cover breast cancer-related medical expenses, had decreased work hours because of breast cancer-related health issues, or been denied job opportunities because of breast cancer. We also assessed the extent to which the costs of prescription medications had been covered by health insurance in the past 12 months.

We defined four race/ethnic groups by using responses from the baseline survey: non-Hispanic whites, non-Hispanic blacks, English-speaking Latinas (ES-Latina), and Spanish-speaking Latinas (SS-Latina), using the Short Acculturation Scale for Hispanics to subdivide the latter two groups. Of note, the three participants who identified as both black and Latina were coded as Latina. We measured other pertinent sociodemographic factors in the baseline survey: age, education, employment status at diagnosis, marital status, and household income. Clinical factors measured in the baseline survey were comorbidity, chemotherapy receipt, radiotherapy receipt, and surgery. SEER records provided clinical stage, and the follow-up survey inquired about breast cancer recurrence.

Analytic Approach

To allow statistical inferences to represent the original targeted population, we applied complex survey weights to the calculation of percentages and regression analyses. Design weights compensated for the oversampling of minorities and disproportionate selection across SEER sites; nonresponse weights compensated for the fact that women with certain characteristics were not as likely to respond to the surveys at each time point, as described further in the Data Supplement. Analyses were conducted by using SAS (SAS/STAT User's Guide, Version 9.2; SAS Institute, Cary, NC).

We compared self-reported financial and employment experiences of survivors by race/ethnicity by using the χ^2 test, limiting analysis to those who could be assigned to one of the four race/ethnic groups. We further constructed two adjusted logistic regression models to evaluate the correlates of decline in financial status attributed to breast cancer, as well as of having experienced at least one type of privation. Both models included the following theoretically selected independent variables: age, race/ethnicity, education, employment status at diagnosis, marital status, household income, comorbidity, stage, chemotherapy receipt, radiotherapy receipt, surgery, breast cancer recurrence, prescription drug coverage during survivorship, reduction in work hours during survivorship, and geographic site. Although missing data for most variables selected for model inclusion were less than 5%, income information was missing for 18.9%, so we employed multiple imputation for missing income data as described in the Data Supplement.

RESULTS

Of 3,133 women surveyed, 2,290 (73%) completed the baseline survey and 1,536 (68%) completed the follow-up, of whom 1,502 could be categorized for race/ethnicity. Table 1 reports the characteristics of these 1,502 patients. The sample was diverse, with 17% black and 40%

Table 1. Baseline Demographic and Clinical Characteristics of the Sample

Characteristic	No.	Weighted % of Sample
Age at diagnosis, years		
< 46	282	21.0
46-55	423	26.1
56-64	396	26.0
65+	401	26.8
Comorbidity		
0	588	41.5
1	456	28.9
2 or more	458	29.6
Race		
White	728	42.7
Black	380	17.4
English-speaking Latina	191	19.5
Spanish-speaking Latina	203	20.4
Education		
High school or less	557	42.1
Some college	510	31.5
College graduate or greater	411	24.4
Missing	24	2.0
Family income at baseline survey		
< \$50,000	637	44.0
\$50,000+	600	36.1
Missing or do not know	265	19.8
Marital status		
Not married or partnered	635	42.0
Married or partnered	849	56.6
Missing	18	1.4
Stage		
0	370	18.1
I	540	34.2
II	416	32.5
III	140	11.8
Missing	36	3.2
Chemotherapy receipt		
No	758	45.4
Yes	691	52.4
Missing	53	2.2
Surgery type		
Breast conservation	994	62.4
Mastectomy without reconstruction	269	21.4
Mastectomy with reconstruction	233	18.2
Radiation receipt		
No	410	31.1
Yes	1,040	66.5
Missing	52	2.5
Work status at diagnosis		
Full time	651	42.4
Part time	196	13.1
Not working	643	43.3
Missing	12	1.2
Geographic site		
Los Angeles	829	79.3
Detroit	671	20.7

breast cancer (for a total of 25% reporting decline attributed at least partly to breast cancer). As Figure 1A depicts, both the proportion reporting decline in financial status ($P < .001$) and the proportion of those who attributed this to breast cancer ($P < .001$) varied

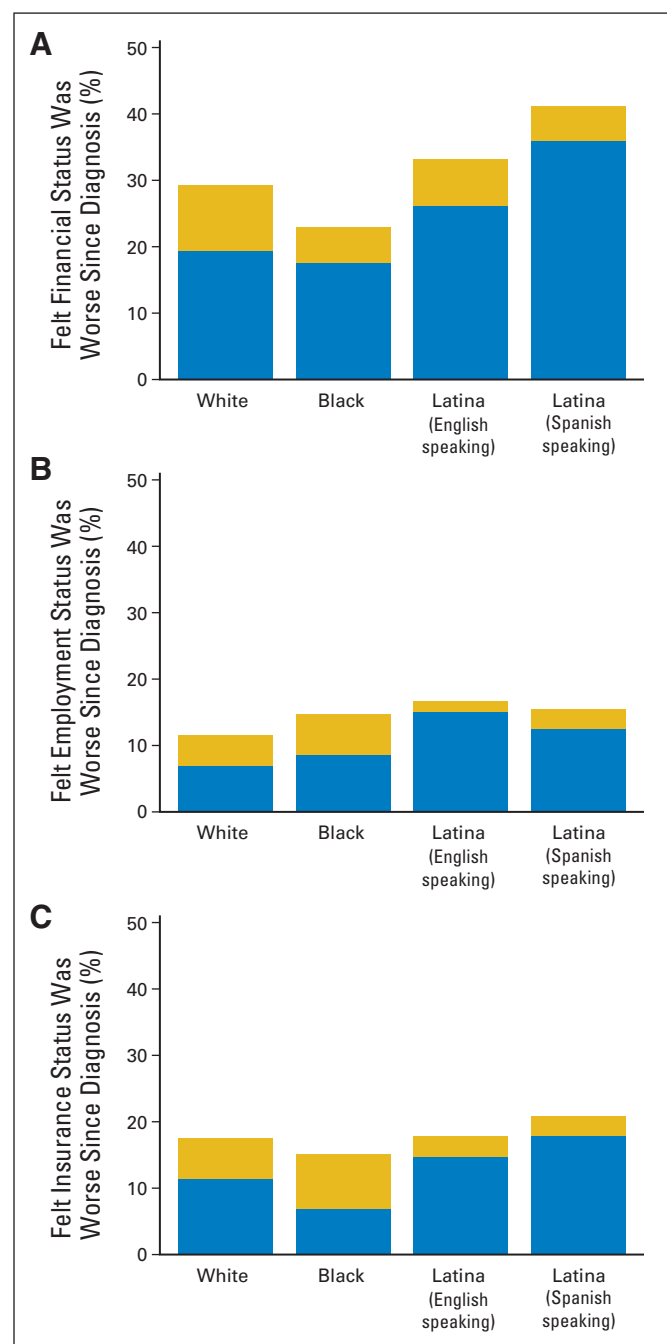


Fig 1. Each bar depicts the percent of respondents who reported being worse off since diagnosis; the blue portion indicates those who attributed this at least partly to breast cancer. (A) The overall proportion of patients reporting decline in financial status varied significantly by race/ethnicity ($P < .001$), as did the proportion attributing decline at least partly to breast cancer ($P < .001$). (B) The overall proportion reporting decline in employment status did not vary by race/ethnicity ($P = .23$), but the proportion of those attributing the decline at least partly to breast cancer did ($P = .005$). (C) The overall proportion reporting decline in insurance status did not vary by race/ethnicity ($P = .52$), but the proportion of those attributing it at least partly to breast cancer did ($P = .006$).

Latina. A total of 52% had stage 0 to I disease, 62% received breast-conserving surgery, and 52% received chemotherapy.

Overall, 33% of respondents reported decline in financial status since diagnosis. Of those, 77% felt this was at least partly because of

Table 2. Multivariable Model of Reporting Decline in Financial Status Attributed at Least Partly to Breast Cancer

Covariate	Worsening Financial Status at Least Partly Due to Breast Cancer (N = 1,244)		
	OR	95% CI	P
Site			
Los Angeles (reference)	1.00		
Detroit	1.07	0.72 to 1.61	.732
Age at diagnosis, years			
< 46	3.99	1.98 to 8.07	< .001
46-55	3.25	1.68 to 6.28	< .001
56-64	2.96	1.63 to 5.37	< .001
65+	1.00		
Race			
White (reference)	1.00		
Black	0.87	0.52 to 1.44	.587
Latina, English-speaking	1.45	0.83 to 2.53	.190
Latina, Spanish-speaking	2.76	1.33 to 5.72	.006
Education			
College graduate or greater	0.77	0.47 to 1.26	.300
Some college/technical school (reference)	1.00		
High school graduate	0.81	0.48 to 1.38	.443
Less than high school	0.67	0.34 to 1.33	.255
Marital status			
Married/partnered (reference)	1.00		
Not married	1.25	0.82 to 1.90	.303
Household income			
\$50,000+ (reference)	1.00		
< \$50,000	1.77	1.04 to 3.00	.034
Working at diagnosis			
Not working (reference)	1.00		
Part time	1.88	1.11 to 3.19	.019
Full time	1.11	0.70 to 1.75	.663
Reduction in work hours			
No (reference)	1.00		
Yes	1.68	1.02 to 2.78	.042
Prescriptions covered by health insurance			
Completely (reference)	1.00		
Mostly	1.09	0.64 to 1.85	.746
Partially	3.67	2.09 to 6.45	< .001
Not covered	2.70	1.27 to 5.73	.010
Comorbidities			
0 (reference)	1.00		
1+	0.84	0.56 to 1.25	.386
Stage of disease			
3	1.92	0.98 to 3.76	.058
2	1.34	0.84 to 2.14	.216
1 (reference)	1.00		
0	1.05	0.61 to 1.80	.869
Surgery			
Lumpectomy (reference)	1.00		
Mastectomy without reconstruction	0.62	0.33 to 1.17	.140
Mastectomy with reconstruction	1.00	0.53 to 1.87	.995
Chemotherapy			
No (reference)	1.00		
Yes	2.14	1.32 to 3.47	.002
Radiotherapy			
No	1.01	0.58 to 1.77	.961
Yes (reference)	1.00		
Recurrent breast cancer			
No (reference)	1.00		
Yes	2.44	1.17 to 5.06	.017

Abbreviation: OR, odds ratio.

significantly by race/ethnicity. Table 2 presents a multivariable logistic regression model, in which SS-Latinas had significantly increased odds of financial decline attributed to breast cancer, as did those with age younger than 65, household income < \$50,000 at diagnosis, part-time employment at diagnosis, reduction in work hours, lack of substantial prescription drug coverage, breast cancer recurrence, and chemotherapy receipt.

As shown in Table 3, the median out-of-pocket spending for breast cancer medical expenses was ≤ \$2,000; 17% of respondents spent > \$5,000. A much lower proportion of SS-Latinas (57%) reported being able to rely on income or savings than other groups (P < .001). ES-Latinas were considerably more likely than other groups to increase credit-card debt to finance their medical expenses (P = .03). Blacks were more likely to report leaving medical bills unpaid (P <

Table 3. Financial Experiences Reported by Breast Cancer Survivors

	Total (%)	Spanish-Speaking Latinas (%)	English-Speaking Latinas (%)	Blacks (%)	Whites (%)	P*
Out-of-pocket spending†						
< \$500	40	64	42	47	25	< .001
\$500-\$2,000	25	20	20	30	28	
\$2,001-\$5,000	18	7	17	16	24	
\$5,001-\$10,000	10	6	12	4	14	
> \$10,000	7	4	10	3	9	
Financing of medical expenses						
Used income and/or savings	80	57	79	81	90	< .001
Borrowed from family or friends	7	10	8	9	4	.04
Borrowed against house	2	0	2	2	2	.41
Left some medical bills unpaid	5	3	5	14	3	< .001
Increased credit card debt	10	6	15	8	10	.03
Debt						
Reporting debt from breast cancer treatment	12	10	17	15	9	.03
Privations						
In past 12 months, because of cost, reported						
Going without medication	5	6	7	6	4	.08
Taking less than fully prescribed amount	4	4	4	6	3	.01
Missing doctor's appointment	8	6	10	11	6	.02
Since diagnosis, because of personal medical expenses, reported						
Going without health insurance	6	8	9	8	2	< .001
Having utilities turned off because of unpaid bills	5	5	4	11	2	< .001
Having to move out of home because could not afford to stay	4	5	6	6	2	< .001

*P values on the basis of comparison across the four race/ethnic groups by using the weighted χ^2 test statistic.
 †Totals do not sum to 100% because of rounding.

.001). Minority respondents were more likely to borrow from family or friends than whites ($P = .04$).

Twelve percent of respondents reported that they had medical debt 4 years postdiagnosis. Debt varied significantly by race/ethnicity, with 9% of whites, 15% of blacks, 17% of ES-Latinas, and 10% of SS-Latinas reporting debt ($P = .03$). As also reported in Table 3, minority respondents were more likely to report foregoing medical care because of cost and other privations because of their medical expenses. At least one privation was experienced by 18% of the sample and, on multivariable analysis, blacks and ES-Latinas were significantly more likely to have experienced at least one privation than whites (Table 4). Other correlates of at least one privation were Detroit location, middle age (46 to 64) compared with younger (≤ 45) or older (≥ 65) age, household income $< \$50,000$, reduction in work hours, and lack of substantial prescription drug coverage.

Overall, 15% of the 1,502 respondents reported decline in employment status since diagnosis, and 72% of these attributed the decline to breast cancer. As depicted in Figure 1B, the overall proportion reporting decline in employment status did not vary by race/ethnicity ($P = .23$), but the proportion of those attributing the decline at least partly to breast cancer did ($P = .005$). Eighteen percent reported that their health insurance status was worse since diagnosis, and of those, 73% felt this was at least somewhat because of breast cancer. As depicted in Figure 1C, the overall proportion reporting that their insurance status was worse did not vary by race/ethnicity ($P = .52$), but the proportion of those attributing being worse off at least partly to breast cancer did ($P = .006$).

Of the respondents, 741 reported that they worked for pay at some time after diagnosis. As detailed in Table 5, in this subgroup, 60% reported that it was at least a little important to work to keep health insurance, 53% to avoid changing jobs because of worry about losing health insurance, and 27% to get a new job in order to get health insurance. Of note, 25% of this subgroup reported that they would look for a new job if they could be assured of comparable benefits (48% of SS-Latinas, 30% ES-Latinas, 24% blacks, and 18% whites; $P < .001$). Of those who worked at some time after diagnosis, 7% had increased work hours to cover cancer-related expenses, 27% had decreased work hours because of cancer-related health issues, and 7% believed they had been denied job opportunities because of cancer.

DISCUSSION

In this sample of long-term breast cancer survivors from two metropolitan areas, one quarter perceived being worse off financially as a result of their breast cancer. Even 4 years after diagnosis, 12% reported having medical debt. Patients reported both economically motivated treatment nonadherence and more general privations related to their medical expenses. Minority patients were most vulnerable to privations and financial decline attributed to breast cancer, even after adjustment for income, education, and employment. To our knowledge, this is the first study to report individual financial experiences in a racially and ethnically diverse sample of patients with breast cancer drawn from population-based registries.

Previous studies have suggested that patients with cancer face substantial financial burden from treatment. Analysis of Medical Expenditure Panel Survey data from 2001 to 2008 suggested that 13.4% of patients with cancer spent $> 20\%$ of income on out-of-pocket

Table 4. Multivariable Model of Reporting at Least One Major Privation Because of Medical Expenses

Covariate	Privations (N = 1,298)		
	OR	95% CI	P
Site			
Los Angeles (reference)	1.00		
Detroit	1.59	1.03 to 2.45	.035
Age at diagnosis, years			
< 46	0.94	0.91 to 0.96	< .001
46-55	3.40	1.63 to 7.12	.001
56-64	1.88	0.97 to 3.61	.060
65+	1.00		
Race			
White (reference)	1.00		
Black	2.62	1.58 to 4.33	< .001
Latino, English speaking	2.17	1.15 to 4.09	.017
Latino, Spanish speaking	1.30	0.53 to 3.18	.559
Education			
College graduate or greater	0.75	0.43 to 1.30	.298
Some college/technical school (reference)	1.00		
High school graduate	1.18	0.68 to 2.06	.557
Less than high school	1.53	0.76 to 3.05	.231
Marital status			
Married/partnered (reference)	1.00		
Not married	1.01	0.66 to 1.56	.960
Household income			
\$50,000+ (reference)	1.00		
< \$50,000	2.05	1.16 to 3.60	.013
Working at diagnosis			
Not working (reference)	1.00		
Part time	1.25	0.66 to 2.38	.489
Full time	1.13	0.68 to 1.86	.646
Reduction in work hours			
No (reference)	1.00		
Yes	2.00	1.20 to 3.33	.008
Prescription covered by health insurance			
Completely (reference)	1.00		
Mostly	1.57	0.84 to 2.91	.155
Partially	4.16	2.17 to 7.99	< .001
Not covered	12.04	5.38 to 26.94	< .001
Comorbidities			
0 (reference)	1.00		
1+	1.05	0.67 to 1.63	.840
Stage of disease			
3	1.23	0.55 to 2.76	.608
2	0.97	0.58 to 1.61	.894
1 (reference)	1.00		
0	1.14	0.66 to 1.99	.639
Surgery			
Lumpectomy (reference)	1.00		
Mastectomy without reconstruction	0.66	0.32 to 1.37	.263
Mastectomy with reconstruction	0.94	0.47 to 1.91	.874
Chemotherapy			
No (reference)	1.00		
Yes	1.54	0.89 to 2.66	.119
Radiotherapy			
No	1.35	0.69 to 2.65	.375
Yes (reference)	1.00		
Recurrent breast cancer			
No (reference)	1.00		
Yes	1.74	0.77 to 3.91	.183

Abbreviation: OR, odds ratio.

Table 5. Employment Experiences Reported by Breast Cancer Survivors Who Worked for Pay at Some Time Since Diagnosis (n = 741)

	Total (%)	Spanish-Speaking Latinas (%)	English-Speaking Latinas (%)	Blacks (%)	Whites (%)	P*
Reporting at least a little important to ...						
Keep working in order to keep health insurance	60	64	68	70	53	.04
Avoid changing jobs because of worry about losing health insurance	53	65	59	59	47	.07
Get a new job to get health insurance	27	54	32	36	16	< .001
Reporting ...						
Would look for a new job if could be assured of comparable benefits	25	48	30	24	18	< .001
Having to increase work hours to cover breast cancer-related medical expenses	7	13	9	2	6	.053
Having to decrease work hours because of breast cancer-related health issues	27	35	33	22	25	.16
Being denied job opportunities because of breast cancer	7	7	9	5	7	.76

health care expenses, including insurance premiums. This burden may translate into significant privations. In a national survey of 930 patients with cancer, 11% reported inability to pay for food, heat, or housing because of the costs of cancer treatment.²⁷ National Health Interview Survey data from 2003 to 2006 suggested that 7.8% of cancer survivors reported forgoing medical care because of cost, although it could not define whether survivors were forgoing cancer care or elective services.²⁸ Financial stress has also been shown to compromise the quality of life in patients with cancer.²⁹

We are aware of only one other survey of patients identified through a population-based registry on this subject.¹⁵ That study focused on colon cancer survivors treated with curative intent, closer to their initial treatment than the long-term breast cancer survivors in the current study. That study also revealed that patients with younger age, minority race, and lower annual household income were more likely to report treatment-related financial hardship. Together, these studies suggest that there is an identifiable subgroup of patients with cancer who are particularly vulnerable to financial distress.

Several studies were conducted to evaluate the out-of-pocket expenses of patients with breast cancer treated one to two decades ago.^{6,30,31} These older studies estimated the monthly out-of-pocket costs for medical expenses incurred by women during chemotherapy to be between \$300 and \$1,180 per month, and approximately \$500 per month by 1 year after diagnosis.³² The findings of the

current study reveal that median total out-of-pocket spending on breast cancer expenses 4 years postdiagnosis was < \$2,000, consistent with a study that revealed that from 1987 to 2001 through 2005, the proportion of cancer costs funded by private insurance increased and the out-of-pocket share decreased.³³ Nevertheless, a substantial minority reported worsening of financial status, and certain subgroups—including those of minority race or ethnicity—appeared particularly vulnerable.

Previous studies have also raised concerns about the effects of cancer on employment, including reduction of income and loss of employment-based insurance, which can in turn adversely affect financial status.³⁴ We found that many survivors reported ways in which cancer influenced their subsequent employment experiences and decisions; concerns about maintaining insurance and benefits were particularly common.

This study has strengths that include its identification of a diverse sample of patients treated in multiple settings through population-based registries, its longitudinal design, and its detailed measures of financial status and burden derived from the broader literature on financial distress. However, a limitation of our study was that we did not compare the experiences of patients in our sample to noncancer control patients. Although we asked patients whether they believed that decline in financial status and privations were attributable to their breast cancer, it is possible that these attributions are inaccurate. Also, as in any survey study, bias may have been introduced by nonresponse. Although the response rate to each of our surveys was high compared with other survey studies of patients with cancer,³⁵ there was attrition in the sample at each step in the longitudinal evaluation, and it is possible that respondents differed meaningfully from those who did not respond. To minimize the impact of nonresponse bias, we employed complex survey weights. Finally, the study was located in two large metropolitan areas, which may limit the generalizability of the findings, particularly to more rural areas and those in which access to Medicaid differs from that in California and Michigan at the time of the study.

Despite these limitations, our findings suggest that a substantial proportion of breast cancer survivors perceive a negative financial impact from diagnosis and treatment, and they experience a variety of privations. Racial and ethnic minorities appeared more vulnerable than whites. Unfortunately, communication between patients and physicians regarding financial concerns is suboptimal.³⁶⁻⁴¹ The current findings should motivate increased efforts to ensure communication between patients and providers regarding the financial implications of cancer diagnosis and treatment decisions. Further research should consider how changes since the time of our study, including the availability of lower-cost generic equivalents for commonly prescribed endocrine therapies, impending changes in Medicaid eligibility mandated by the Affordable Care Act, and the creation of a federal Consumer Financial Protection Bureau to regulate consumer credit more tightly, may have modified the experiences of patients currently being diagnosed, as compared with those reported by the patients in our study. Additional research is also important to further define the long-term financial experiences of patients with other types of cancer, whose experiences may differ from those in our sample for various reasons (including differences in treatments, prognosis, and insurance eligibility), as well as the predictors for vulnerability to financial decline and privations in those settings, to allow for the rational targeting of interventions and support.

Although we are deservedly proud of advances in our ability to cure an increasing proportion of patients diagnosed with breast cancer, we must ensure that we do not leave them in financial ruin as a result of our efforts. Providers, researchers, and policymakers alike must make dedicated efforts to reduce the cost of medical care in order to help prevent the lasting deleterious impact on the financial well-being of patients of the sort observed in this study.

AUTHORS' DISCLOSURES OF POTENTIAL CONFLICTS OF INTEREST

The author(s) indicated no potential conflicts of interest.

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Appendix

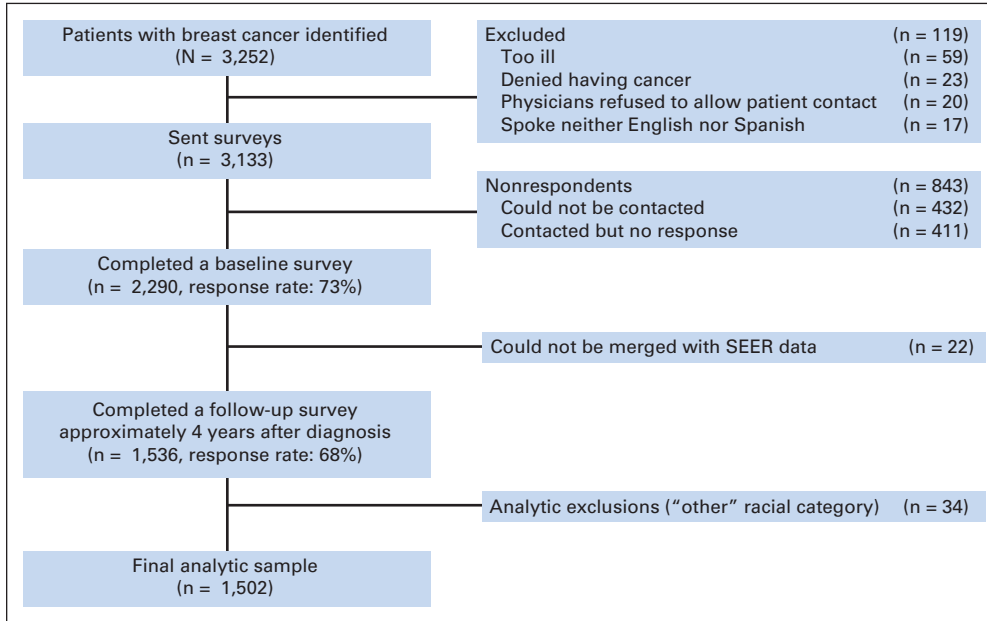


Fig A1. This figure depicts the evolution of the analytic sample of women diagnosed with breast cancer in metropolitan Los Angeles and Detroit. Cases were initially selected on the basis of rapid case ascertainment, which lacks the level of quality control that is ultimately used to determine inclusion in the SEER registry. Certain cases that were initially identified and surveyed were ultimately excluded from SEER because they were no longer considered to be reportable cases after quality control; as shown above, 22 cases could not be merged to SEER and were therefore excluded from the sample.