INTRODUCTION
There are currently an estimated 3.1 million breast cancer survivors in the United States,1 a number that is projected to grow to 4.5 million in the next 10 years given steady or increasing incidence2,3 and decreasing mortality.4 Current 5-year survival rates approach 90%, and recent advances in detection and treatment suggest that many will exceed this in future years but will be at risk for experiencing long-term adverse treatment effects.1 In the United States, patients who have breast cancer experience significant economic burden, even compared with those who have other types of cancer.1-8 The economic burden after cancer may be further exacerbated for patients who are managing adverse treatment effects, such as breast cancer-related lymphedema,9,10 which is one of the most common and costly breast cancer-related adverse treatment effects, affecting nearly 35% of breast cancer survivors in the United States11,12 and resulting in an estimated $14,877 in out-of-pocket costs in the first 2 years of a diagnosis.13 Even up to 10 years after diagnosis, out-of-pocket health costs for women who have breast cancer-related lymphedema are more than double the costs for those without breast cancer-related lymphedema.14 The associated economic burden is so significant that it even affects the insured.5-7,10-23 Cancer survivors with public insurance experience even greater economic burden than those with private insurance,24,25 which is exacerbated for those who have lymphedema, because many public insurance plans do not cover compression bandages or garments for self-management of lymphedema.26 Those with limited resources or few financial reserves may experience the most challenges after diagnosis.27-29

BACKGROUND: In the United States, patients who have breast cancer experience significant economic burden compared with those who have other types of cancers. Cancer-related economic burden is exacerbated by adverse treatment effects. Strategies to resolve the economic burden caused by breast cancer and its adverse treatment effects have stemmed from the perspectives of health care providers, oncology navigators, and other subject-matter experts. For the current study, patient-driven recommendations were elicited to reduce economic burden after 1) breast cancer and 2) breast cancer-related lymphedema, which is a common, persistent adverse effect of breast cancer.

METHODS: Qualitative interviews were conducted with 40 long-term breast cancer survivors who were residents of Pennsylvania or New Jersey in 2015 and were enrolled in a 6-month observational study. Purposive sampling ensured equal representation by age, socioeconomic position, and lymphedema diagnosis. Semistructured interviews addressed economic challenges, supports used, and patient recommendations for reducing financial challenges. Interviews were coded, and representative quotes from the patient recommendations were analyzed and reported to illustrate key findings.

RESULTS: Of 40 interviewees (mean age, 64 years; mean time since diagnosis, 12 years), 27 offered recommendations to reduce the economic burden caused by cancer and its adverse treatment effects. Nine recommendations emerged across 4 major themes: expanding affordable insurance and insurance-covered items, especially for lymphedema treatment (among the 60% who reported lymphedema); supportive domestic help; financial assistance from diagnosis through treatment; and employment-preserving policies.

CONCLUSIONS: The current study yielded 9 actionable, patient-driven recommendations—changes to insurance, supportive services, financial assistance, and protective policies—to reduce breast cancer-related economic burden. These recommendations should be tested through policy and programmatic interventions.

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KEYWORDS: breast cancer, economic burden, lymphedema, qualitative analysis, United States.
Studies documenting the impact of economic burden on cancer survivors have explored provider-driven recommendations\textsuperscript{30-32} and oncology navigator perceptions\textsuperscript{33} for reducing economic burden. Provider-driven recommendations largely focus on addressing elements of the health care system and direct medical costs,\textsuperscript{30-32} such as payments made for health needs by the patient or insurer. Yet, from a patient perspective, economic burden includes more than direct costs. Patient-driven recommendations go beyond direct medical costs to address: psychosocial costs; indirect costs, such as employment losses; time costs; and nonmedical direct costs, such as transportation to medical visits.\textsuperscript{34} For example, one study of patient-driven recommendations identified the need for affordable insurance, prompt information on costs, and access to social workers, navigators, and support groups knowledgeable about resources to reduce economic burden.\textsuperscript{35} However, that study only included older breast cancer survivors from one safety-net clinic; therefore, an assessment of breast cancer survivors across age groups, insurance, and health care systems might yield new or different findings.

The objective of the current study was to provide a broader assessment of patient-driven recommendations by including diverse perspectives across age, insurance status, and race through qualitative analysis of interviews with 40 long-term breast cancer survivors. Qualitative data can enhance our understanding of how economic burden operates over the course of survivorship. Patients have first-hand experience in navigating insurance and seeking eligibility for programs to help mitigate economic burden. Documenting patients’ experiences through qualitative analysis can provide key insights into how to reduce economic burden.

MATERIALS AND METHODS

Sample
From May to September of 2015, 258 women were screened by phone for study eligibility. This 6-month observational study included former participants from the Physical Activity and Lymphedema trial (n = 295)\textsuperscript{36,37} who were still alive or participants who were ineligible (n = 163) for the ongoing Women in Steady Exercise Research Survivor Study (clinicaltrials.gov identifier NCT01515124)\textsuperscript{38} but met requirements for entry into the Physical Activity and Lymphedema trial to ensure that samples were comparable. All participants who had consented to be re-contacted about future studies and had up-to-date contact information were contacted. Eligibility criteria included: women with stage I through III, invasive breast cancer; completion of active breast cancer treatment; >1 lymph node removed; and current residence in Pennsylvania or New Jersey. Additional details of study recruitment have been previously published.\textsuperscript{39} In total, 129 women enrolled in the study, and 40 of these women were selected for a qualitative interview. Purposive sampling was used to ensure equal representation across lymphedema status, age group (>65 years and <65 years), and socioeconomic position (using education level as a proxy). Participants were randomly sampled from within each demographic category, with at least 10 in each demographic group.

Ethical Considerations and Informed Consent
The Institutional Review Board of the University of Pennsylvania approved this study. Written informed consent was obtained from each individual participant.

Data Collection
At baseline, participants completed a demographic and health history survey, including a report of previous lymphedema diagnosis by a health professional. Participants completed a follow-up survey on economic burden and interviews at 6 months (November 2015 to January 2016). Economic burden after cancer was assessed based on items adapted from the Breast Cancer Finances Survey,\textsuperscript{40,41} a survey of economic burden that has been validated among breast cancer survivors, with scores ranging from 0 to 12 (higher values corresponded to greater economic burden). The principal investigator developed the standardized, semistructured interview guide (Supporting Materials), which addressed economic challenges, supports used, and patient recommendations for reducing long-term economic impacts of breast cancer. Both the principal investigator and a trained research assistant conducted interviews. Interviews lasted approximately 15 to 30 minutes and were conducted in private rooms at the study site. Recordings were de-identified and transcribed verbatim.

Data Analysis
For descriptive statistics, means and standard deviations were calculated for continuous variables, and the number and percentage of participants were calculated for categorical variables. For qualitative analysis, transcripts were imported into the MAXQDA software program (VERBI Software, Berlin, Germany), a data analysis program used for systematizing, organizing, and analyzing qualitative data. Qualitative data analysis software does not itself
suggest interpretations but allows the researcher to draw conclusions through a systematic coding and comparison of the text. First, structural codes were identified based on the relevant economic burden domains previously identified in the research literature.34 Initial structural codes included: change in financial attitudes, lasting impact of cancer economic burden, sacrificing things of value, cost shifted to other parties, psychosocial costs, productivity losses, time costs, insurance, out-of-pocket costs, compromising health because of cost, patient recommendations (for reducing costs), lymphedema, and lymphedema treatment. A separate code denoted when a patient gave a specific recommendation. Next, the research team organized all codes into a codebook. Each fifth transcript was coded by 2 analysts. Discrepancies were discussed and resolved among the research team. Finally, representative quotes from the “patient recommendations” code were reported to illustrate key findings. To protect the confidentiality of study participants, we used pseudonyms in reporting the results.

RESULTS
The descriptive statistics provided in Table 1 were based on 40 interviewees. The mean age of interviewees was 64 years. Less than one-half of participants were black (42.5%), slightly more than one-half (53%) were white, and the remaining 5% identified as another race. Most interviewees (53%) were college graduates or had received graduate degrees. Approximately 11% had an annual income <$30,000, and a plurality had an annual income between $30,001 and $70,000 (58%); on average, a household income supported 2 individuals average. More than 1 in 3 interviewees had cash assets totaling <$5000 (35.1%), and 27% each had assets totaling between $5000 and $49,999 or between $50,000 and $499,999. The remaining 11% of interviewees had cash assets >$500,000. The average economic burden score was 2.5, reflecting low economic burden among these long-term breast cancer survivors; there was no significant difference in economic burden by lymphedema status. All interviewees had health insurance, and the vast majority had private insurance (82.5%). Approximately 62% were diagnosed at stage 0 or 1, and 39% were diagnosed at stage 2 or 3. The remaining 23% were missing information on disease stage at diagnosis and could not be categorized. The mean time since diagnosis was 12 years. Most interviewees received chemotherapy (77%) and radiation (83%), and one-quarter also received hormonal therapy (25%). Participants had a mean of 2 comorbidities. Over one-half of the women (60%) experienced breast cancer-related lymphedema.

Qualitative Findings
Of all 40 interviewees, 10 did not offer any recommendations, and 3 made recommendations unrelated to reducing economic burden. Twenty-seven participants offered recommendations related to reducing economic burden. Patient recommendations to reduce economic burden were grouped into 4 major areas for improvement: insurance, supportive services and care, financial assistance, and protective policies. Patients offered 9 specific recommendations across the 4 domains. Tables 2 through 3 provide representative quotes of challenges patients experienced and suggestions for change.

TABLE 1. Demographic Characteristics of Interviewees, N = 40

| Variable                        | No. of Interviewees (%) |
|--------------------------------|-------------------------|
| Demographics                   |                         |
| Age: Mean ± SD, y              | 64 ± 8                  |
| Race                           |                         |
| Black                          | 17 (42.5)               |
| Other                          | 2 (5.0)                 |
| White                          | 21 (52.5)               |
| Education completed            |                         |
| High school                    | 19 (47.5)               |
| College                        | 12 (30)                 |
| Graduate school                | 9 (22.5)                |
| Race                           |                         |
| Black                          | 17 (42.5)               |
| Other                          | 2 (5.0)                 |
| White                          | 21 (52.5)               |
| Total cash assets              |                         |
| ≤$4999                         | 12 (35.1)               |
| $5000-$49,999                  | 10 (27.0)               |
| $50,000-$499,999               | 10 (27.0)               |
| ≥$500,000                      | 4 (10.8)                |
| Economic burden score: Mean ± SD [range] | 2.5 ± 4 (0-12) |
| Insurance type                 |                         |
| Public                         | 12 (30.0)               |
| Private                        | 33 (82.5)               |
| None                           | 0 (0.0)                 |
| Cancer stage at diagnosis      |                         |
| 0                              | 10 (32.3)               |
| 1                              | 9 (29.0)                |
| 2                              | 7 (22.6)                |
| 3                              | 5 (16.1)                |
| Missing                        | 9 (22.5)                |
| Time since diagnosis: Mean ± SD, y | 12 ± 5               |
| Radiation                      | 33 (82.5)               |
| Chemotherapy                   | 30 (76.9)               |
| Hormone therapy                | 10 (25.0)               |
| Comorbidities                  | 2 (1.0)                 |
| Have lymphedema, +BCRL         | 24 (60.0)               |

Abbreviations: +BCRL, diagnosed with breast cancer-related lymphedema; SD, standard deviation. *Percentages sum to greater than 100% because participants could be simultaneously participating in public and private insurance plans.
| Domain                        | Specific Focus                             | Representative Quote (Age, Lymphedema Status, and Economic Burden Score When Available) | Specific Recommendation                        |
|-------------------------------|--------------------------------------------|--------------------------------------------------------------------------------------|------------------------------------------------|
| Insurance                     | Insurance navigation                       | I think insurance is always a challenge, because... I'll give you one example: I went to my gynecologist, and he ordered for me to get an MRI, because I can't do a mammogram, having implants. We got the MRI, and the insurance refused to pay for it. I went through all the appeals I could. I even talked to one of our state representatives, because I fought it as rigorously as I could, and I ended up paying over $2000 out of pocket. I sent them pages and pages of information, it was consuming so much of my time, oh, it was endless; it was the emotional feeling that an insurance company could do that to you. (Frances, age 56 y, −BCRL, EBS = 0) | Provide assistance understanding insurance coverage |
| Quality of insurance coverage |                                            | Yeah, I wish there was some place that you could either go, or call, or whatever, that really understood how Medicare worked. (Jill, age 73 y, −BCRL, EBS = 7) | Provide assistance with navigating changes in insurance coverage |
| Affordable insurance coverage |                                            | What could have helped me? Just more financial aid, really, because, like I said, when I first started out, I was with [one insurance], and they were taking care of it. I was getting the bras. I was getting the sleeve. Then, all of a sudden, oops [no more coverage for those items]. (Meredith, age 66 y, +BCRL) | Ensure high-quality insurance coverage |
| Insurance coverage for and access to lymphedema treatment |                                            | My COBRA had expired... I couldn't afford to pay $1000 a month for insurance... Then, when I turned 65, I was qualified for Medicare. But Medicare... But I didn't have half of the coverage that I had [before]. So, the first thing I would say is to really check out what kind of insurance plans you have. Because I think it really does make a big difference. (Francis, age 66 y, +BCRL, EBS = 2) | Insurance coverage or financial support to promote accessibility to physical activity |
|                                            |                                            | My copays were not that expensive. Like I said, I had a pretty good insurance, so actually they paid for most everything. I believe at the time my copays were actually like $10. (Rachel, age 49 y, +BCRL, EBS = 0) | Keep co-pays, premiums and deductibles low |
|                                            |                                            | ...Exercise, that's really important. I exercised a lot before I was diagnosed, so maybe that kind of sort of helped me and then I continue to—as much as I could, when I felt real good. (Elizabeth, age 55 y, −BCRL, EBS = 0) | Expand coverage for lymphedema-specific materials |
|                                            |                                            | I really do not think that issues that are direct outcomes of the type of cancer, people should have to have a co-pay for them to be treated, that you should have these exorbitant rates. (Susannah, age 62 y, −BCRL, EBS = 4) | Expand coverage for lymphedema-specific materials |
|                                            |                                            | This year, for my daughter (age 20 y), and myself, it is $820/mo for insurance with a $6000 deductible. This year, we got kicked out to the marketplace (ACA) and could have gone with a cheaper policy, but I was afraid, if I got sick, then what would happen? (Frances, age 56 y, BCRL, EBS = 0) | Expand coverage for lymphedema-specific materials |
|                                            |                                            | The only thing that wasn't covered was... a shot that I had to take the next day [after chemotherapy treatment], and it was called a Neulasta (pegfilgrastim) shot, and that shot was a $100; and, for—I think for someone that's not employed, that would be a difficult fee for them to have to pay, but since I worked, you know, it really wasn't, like, a burden or anything. (Elizabeth, age 55 y, −BCRL, EBS = 0) | Expand coverage for lymphedema-specific materials |
Insurance
Women in our study with and without breast cancer-related lymphedema felt that it was challenging to navigate the insurance system and would have benefited from a navigator to explain the process to them (Table 2). Frances’ (aged 56 years, no lymphedema) quotation illustrates how, although using insurance should be cost saving, it actually can cost the patient time and money and contributes to anxiety out of a sense of not knowing what would happen. The quotation highlights the gap between what patients need and what insurance companies are willing to cover without additional effort by the patient. Elizabeth (aged 55 years, no lymphedema) noted that having stable employment and income was critical to obtaining necessary cancer-related treatments not covered by insurance. Her comment reflects the reality that patients pay out-of-pocket for items that are not covered by insurance and thus need to maintain employment and a source of income to afford those noncovered items. Participants emphasized that having quality insurance that included coverage for cancer care and lymphedema treatment helped to minimize out-of-pocket costs, psychosocial costs (such as stress or anxiety), and time costs.

Interviewees also emphasized the importance of affordable insurance coverage. Those with breast cancer-related lymphedema faced additional issues in getting insurance to pay for lymphedema self-management supplies. Garments, tape, and bandages must be replaced several times a year, which poses ongoing, lifetime costs that accumulate. Phyllis (age 74 years, has lymphedema) described forgoing lymphedema management because compression garments and bandaging were not covered by her insurance and cost up to $300 for garments and $100 for bandages and tape. Other patients mentioned that complementary and alternative medicine procedures, like acupuncture to reduce lymphedema-related swelling, generally were not covered by insurance, but should be. Specific recommendations for insurance included the following:

Recommendation 1
Provide assistance with understanding what is covered under insurance and how to navigate changes when switching to a new insurance provider.

Recommendation 2
Ensure high-quality insurance that covers required and elective cancer-related services with low co-pays, premiums, and deductibles.

Recommendation 3
Expand insurance coverage for lymphedema-specific materials and lymphedema management, including long-term physical therapy and complementary and alternative medical treatments.

Supportive Services and Care
The most commonly mentioned suggestion was psychosocial support to reduce the psychosocial costs of stress and anxiety (Table 3). Patients mentioned support groups as a way to connect with other women to seek recommendations about treatments, hospitals, and services they could use postdiagnosis. Among those who did not use...
support groups, common problems included: groups were not available local, and long distances had to be traveled; feeling that the information needed to be tailored more to their specific health care needs; or simply not knowing where to find groups until late in the treatment process. Some patients suggested an individual buddy or “cancer pal” would be preferable to a support group because of the private and individualized treatment plans and needs of each patient. Furthermore, among the interviewees without lymphedema reported that exercise improved feelings of well being; however, such regimens must be specific to the patient’s needs and physical abilities.

The supportive services recommended included physical support, such as home health care, childcare,
transportation, and housekeeping. Chemotherapy can be fatiguing, and postsurgery and reconstruction guidelines severely restrict movement. Furthermore, postsurgery care guidelines can be overwhelming and may lead to confusion and side effects. Emma (aged 57 years, has lymphedema) discussed how a lack of home health care for surgical drains led to an infection. These challenges were present although she lived with other individuals. Specific recommendations for supportive services and care included the following.

**Recommendation 4**
Address psychosocial costs by expanding support groups and buddy services.

**Recommendation 5**
Expand the availability of home health care services after cancer treatment.

**Recommendation 6**
Provide domestic assistance with household chores, childcare, and transportation.

**Financial Assistance**
Women also identified a lack of programs, or knowledge about programs, designed to financially assist women who were above the poverty line (Table 4). Interviewees felt that the process of finding financial support was challenging, because: 1) there were no referral services available, or 2) eligibility was limited, and 3) procuring assistance involved contacting multiple programs and incurring time costs. Several patients mentioned that grant programs for wigs and lymphedema garments available through hospitals or nonprofit organizations were helpful to them; however, others stated that their financial need was not deemed high enough to participate in these programs, yet they still could not afford their health needs.
Outside of explicit financial assistance, women with lymphedema felt they would benefit from financial planning services. Oncology centers could create a list of resources to present at diagnosis. Interviewees suggested that screening and referral to financial services could occur during or near oncology visits and could be provided early on in the cancer treatment process at hospitals and insurance companies. Patients want to be made aware of financial services or resource navigators who could assist in explaining insurance coverage. These resources would benefit women so that, if they do find themselves facing a new challenge, then they already would have a point of reference to seek assistance. Specific recommendations related to financial assistance included the following.

**Recommendation 7**
Expand eligibility for financial aid and social services to those who are not in poverty.

**Recommendation 8**
Provide financial counseling or navigation throughout the diagnosis and treatment process.

**Protective Policies**
Women with and without lymphedema all identified concerns about uncertainty regarding employment after their breast cancer treatment (Table 5). Although the Family and Medical Leave Act (FMLA) continues health insurance and offers job restoration, it does not replace income. Because some employers are excluded from FMLA requirements, patients with cancer can be subject to individual company policies, some of which may be more comprehensive than others. Given the limitations of existing policies, some participants used short-term disability insurance, which replaces a portion of income but does not preserve health insurance or employment and is a voluntary program for employers in most US states. Patients pointed to the insufficiency of time to recover provided by existing policies, the need for legislation that could extend beyond the existing 12 weeks provided by the FMLA, and greater protections to return to employment without penalty. They made the following specific recommendation for protective policies.

**Recommendation 9**
Expand policies that protect employment and medical leave to offer more acceptable leave time.

### DISCUSSION

Patient recommendations for reducing economic burden after breast cancer focus on expanding insurance coverage, social services, and employment-preserving policies. Our findings align with previously reported patient recommendations for affordable insurance, prompt information on costs, and access to financial navigation and peer support. In addition, the current study expands on previously mentioned recommendations to include additional cost-saving services and policies that could be offered or improved. In alignment with provider-based recommendations, patients suggest institutional changes in health care system delivery and in which treatments are covered by insurance as standard. Patients want existing structures to be improved, which may decrease distrust in the health care system. Overall, patients want protection from the cascade of economic burden, and full protection would require additional insurance coverage and services for those who are managing a long-term, adverse treatment effect like breast cancer-related lymphedema.

### TABLE 5. Patient-Driven Recommendations for Improving Policies to Preserve Employment After Breast Cancer

| Domain | Specific Focus | Representative Quote (Age, Lymphedema Status, and Economic Burden Score, When Available) | Specific Recommendation |
|--------|----------------|------------------------------------------------------------------------------------------|-------------------------|
| Protective policies | Policies protecting employment | The job I was working on terminated me and didn’t inform me that I was terminated, because I was out more than 3 mo… | Expansion of time covered by FMLA beyond 12 wk |
| Workplace policies, some sort of legislation that says, you know, just—maybe an amendment with the FMLA, that if someone is going through documented chemo and radiation…if you have an employee who has been exemplary for X amount of years and is hit with something like this…you can’t just move them off the map and forget about them; they have the right to come back. (Cheryl, age 52 y, −BCRL, EBS = 7) |

Abbreviations: +BCRL, diagnosed with breast cancer-related lymphedema; −BCRL, no history of breast cancer-related lymphedema; EBS, economic burden score; FMLA, Family and Medical Leave Act.

*To protect the confidentiality of study participants, pseudonyms are used in reporting the results.*
For each domain, specific suggestions from the literature are offered on how to implement patient-driven recommendations. Implementing the changes suggested requires action by various parties, and there is no single entity that can resolve the challenge of high out-of-pocket costs for breast cancer survivors. Although the value in this analysis is that it provides patient-driven recommendations for reducing economic burden, the patient perspective is one viewpoint, and patients may not be able to perceive how their interests in changing various elements involved in health care delivery might interact or conflict. Still, patients live the reality of health care delivery, and their thoughts on how it can be improved add value to decision-making processes.

**Insurance**

Patients consistently pointed to a need for help with insurance navigation, although they did not identify who should provide this service. Navigating insurance systems requires problem-focused coping skills, which have both time and psychosocial costs. The costs to overcome these challenges may be too overwhelming for patients with cancer who may be undergoing active or adjuvant therapy. Thus navigators could help to reduce stress by identifying pathways for patients based on their specific financial and health needs. Insurance navigation could be integrated into the roles of patient navigators or social workers at the hospital. Navigation services might be covered by the hospital system itself or in collaboration with insurers.

Having quality insurance was associated with minimizing burdensome out-of-pocket costs, and those with the lowest economic burden believed it was because they had “good insurance.” Patients incur substantial out-of-pocket costs and may not know whether such costs could be covered by insurance. This was especially true among those with lymphedema; although the Patient Protection and Affordable Care Act was successful in expanding affordable insurance coverage for cancer-related care, it did not address the adverse treatment effects of cancer. Studies before the 2010 Affordable Care Act reported that financial burden created worry and anger when tools for lymphedema management were not covered by insurance. Our findings suggest that insurance expansion for cancer has not filled the insurance gap for patients with lymphedema; however, some states have designed legislation specifically to address lymphedema. A study in one state demonstrated that expanding coverage for lymphedema services and treatment lowered patient out-of-pocket costs and lymphedema-related hospitalizations while having a less than 0.1% impact on costs for insurance claims and less than a 0.2% impact on insurance premiums after 10 years. Legislation requiring that private insurance plans cover lymphedema treatment has passed in California, Louisiana, North Carolina, and Virginia, but bills introduced to require lymphedema treatment coverage have not been adopted nationally at the Congressional level. To reduce economic burden after cancer, patients who are diagnosed with breast cancer-related lymphedema should have expanded access and insurance coverage of lymphedema services, including education, physical therapy, and supportive garments. Economically disadvantaged patients may benefit the most from increased insurance coverage.

Patients also suggested expanding coverage for complementary and integrative medicines. Subramani et al observed that most patients with cancer did not receive instructions about such medicines from their physician, which our study corroborates. Both expanded insurance coverage and physician education could increase the awareness and use of complementary and integrative medicines among patients with cancer.

Although patients consistently suggested expanding what insurers cover, shifting costs back onto insurers may not be enough to reduce economic burden, especially if third-party payers find other ways to pass costs back to patients. This may happen through increased premiums, deductibles, co-insurance, cost-sharing, or tiering medication, as has been done with oral anticancer medications. Subsequently, several states have considered or passed bills that limit patient cost-sharing, which indicates that even changing insurance has implications for other sectors. Although insurance providers are only one part of the solution to the challenge of economic burden, changes to insurance would require efforts and changes by patients, providers, insurers, state and federal policy-makers, and the pharmaceutical industry. There may be alternative approaches to minimizing cost and maximizing care, especially when that care occurs outside of the traditional health care setting. Top-down and bottom-up strategies that involve all parties are warranted.

**Supportive Care and Services**

Patient recommendations around supportive care and services highlight how nonmedical services and instrumental support can help reduce financial, psychosocial, and time costs. Existing programs that currently provide home health care could be expanded and leveraged. For example, mortgage deferment services can be used to reduce
expenses that could then be used for cancer treatment. These incentives could be offered directly by mortgage companies, which might be an incentive that makes the mortgage company attractive to potential clients. Private companies, including ride-share and home-share services as well as cancer-focused nonprofits, already provide some of these services.  

States that have respite care provider services might expand their services to include home care for those patients who recently completed cancer treatment. This expansion could offer additional help with household chores and childcare. Existing transportation infrastructure (eg, community-based ride-sharing programs) designed for those with disabilities or illnesses could be leveraged to expand transport services for cancer-related medical visits. These services may be especially helpful for patients with lymphedema, who may have less ability to perform activities of daily living during bouts of lymphedema. Changes to these support systems likely would require support from a state governor or state congress to expand the budgets and scopes of these existing services.

Financial Assistance
Implementing recommendations for financial services would need to start with identifying patients through screening for risk of economic burden at the time of treatment. This may point to a need to go beyond income or poverty thresholds to determine need. Rather than basing financial need on poverty guidelines, financial need might be determined by whether or not the patient has access to additional resources. Indicators like consumer credit scores, which suggest access to resources beyond tangible income, may be a novel screening tool for identifying who might be at risk for high economic burden and who would benefit best from an intervention. Charitable assistance organizations or state financial assistance programs could reconsider whether their guidelines should be based on the federal poverty guidelines or could increase the flexibility of their eligibility requirements in response to unique situations.

Financial navigation has been previously suggested by health care providers, and our current results suggest that patients would support the role of a financial navigator. Recent pilot interventions with short-term financial navigators have suggested that navigation programs can substantially reduce anxiety about costs, although self-reported financial burden did not substantially change. Without lowering financial burden, making individual patients aware of the costs still puts a premium on health and may exacerbate disparities, because those with the greatest resources will be able to afford better health services. Our findings align with other recent findings of patients’ desire for physicians to have some of these conversations, whereas clinicians have expressed concerns about appropriateness, ability to supply accurate information, and time barriers. Although physicians could provide a list of references for patients to seek financial counseling in their offices, as patients suggested, this approach may increase their time costs; therefore, automatic referral by the physician or by another member of the health care team to a program that is integrated within the health system may be more efficient.

Protective Policies
Breast cancer survivors have reported many challenges with employment, despite the existing protective policies in place in the form of the FMLA and short-term disability. In the United States, the FMLA allows eligible employees to take up to 12 work weeks of unpaid continuous or intermittent leave in a 12-month period (or up to 26 weeks for an eligible military service member). After returning from leave, employees must be restored to their original job or to an equivalent job with equivalent pay, benefits, and other terms and conditions of employment. Certain small private employers, public agencies, or public schools are exempt, and employees must meet eligibility requirements. Although the FMLA is a step toward preserving employment, participants suggest that it needs to be expanded, especially because active cancer treatment and associated recovery may take 6 months or more. Expanding the FMLA would require action by the US Congress and the US Department of Labor, although some states have enacted more expansive FMLA regulations.

Patients who can access the FMLA and short-term disability programs concurrently may be in the best position to navigate economic shocks because of cancer, but it is unclear how many individuals are dually eligible. Financial counseling that addresses options for the FMLA and for short-term and long-term disability may be warranted. Redesigning sick leave policies to better accommodate chronic disease needs has been previously suggested, and the current analysis supports patients’ perceptions that changes to these programs would reduce the economic burden after cancer.

Limitations
All participants in this study were from the East Coast, currently insured, and had low overall economic burden.
Responses may be different from women who live in regions with other insurance offerings. Because this was a voluntary research study, those who experienced the greatest economic challenges may not have had time to enroll and participate, indicating that our results may underestimate the economic burden. Also, the current results may not be generalizable to other tumor sites, but breast cancer is among the most economically burdened cancers. No interviewees were receiving active cancer treatment at the time of this study. Instead, survivors were the focus, because they could provide perspectives on the long-term economic impact of breast cancer. In most cases, respondents did not identify who should enact the recommended changes; however, in some cases, the target for change could be concluded (eg, changes in the FMLA would require an act of Congress).

Conclusions
Without changes, out-of-pocket costs will continue to be a challenge for the growing number of breast cancer survivors in the United States. This qualitative study adds to the literature by representing the patient perspective on reducing economic burden after breast cancer and providing 9 specific recommendations for changes to insurance, supportive services, financial assistance, and protective policies. It includes specific input from a diverse group of long-term cancer survivors, including those living with a long-term adverse treatment effect of cancer that requires ongoing management. The current recommendations are actionable and should be explored further in testable policy and programmatic interventions. Future studies might consider comparative viewpoints of these recommendations from various members of the health care, insurance, and policy-making communities.

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CONFLICT OF INTEREST DISCLOSURES
The authors made no disclosures.

AUTHOR CONTRIBUTIONS
Lorraine T. Dean contributed to all parts of the study process, from conceptualization through writing. Shadiya L. Moss contributed to the conceptualization, formal analysis, and project administration. Sarah I. Rollinson and Livia Frasso Jaramillo contributed to the formal analysis, data visualization, and methodology. Raheem J. Paxton and Jill T. Owczarzak contributed to data interpretation of the analysis. All authors contributed to the original draft and reviewed and edited the final version.

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