


Patient Recommendations for Reducing Long-Lasting Economic Burden After Breast Cancer

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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. *Cancer* 2019;125:1929-1940. © 2019 The Authors. *Cancer* published by Wiley Periodicals, Inc. on behalf of American Cancer Society. This is an open access article under the terms of the Creative Commons Attribution-NonCommercial License, which permits use, distribution and reproduction in any medium, provided the original work is properly cited and is not used for commercial purposes.

KEYWORDS: breast cancer, economic burden, lymphedema, qualitative analysis, United States.

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 incidence^{2,3} and decreasing mortality.³ 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.⁴⁻⁸ The economic burden after cancer may be further exacerbated for patients who are managing adverse treatment effects,⁹⁻¹⁴ such as breast cancer-related lymphedema,^{15,16} 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 States^{17,18} and resulting in an estimated \$14,877 in out-of-pocket costs in the first 2 years of a diagnosis.¹⁵ 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.¹⁹ The associated economic burden is so significant that it even affects the insured.^{5,20-24} 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

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Additional supporting information may be found in the online version of this article.

DOI: 10.1002/cncr.32012, **Received:** July 15, 2018; **Revised:** November 27, 2018; **Accepted:** January 11, 2019, **Published online** February 22, 2019 in Wiley Online Library (wileyonlinelibrary.com)

Studies documenting the impact of economic burden on cancer survivors have explored provider-driven recommendations³⁰⁻³² and oncology navigator perceptions³³ for reducing economic burden. Provider-driven recommendations largely focus on addressing elements of the health care system and direct medical costs,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.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.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 ($n = 295$)^{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)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.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,^{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

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)
Annual income	
≤\$30,000	4 (10.5)
\$30,001-\$70,000	22 (57.8)
>\$70,000	12 (31.6)
No. of supports used: Mean ± SD	2 ± 1
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 ^a	
Public	12 (30.0)
Private	33 (82.5)
None	0 (0.0)
Clinical variables	
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.

^aPercentages sum to greater than 100% because participants could be simultaneously participating in public and private insurance plans.

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 2. Patient-Driven Recommendations for Improving the Insurance System for Women With a History of Breast Cancer

Domain	Specific Focus	Representative Quote (Age, Lymphedema Status, and Economic Burden Score When Available) ^a	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) 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 understanding 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 68 y, +BCRL) 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)	Provide assistance with navigating changes in insurance
	Quality of insurance coverage	... They wanted me to have shots of Neupogen (filgrastim), and that wasn't covered, but then apparently it was covered under major medical... But that could've been a problem, because I think at the time the shots were, like, \$1500 apiece. (Eve, age 59 y, -BCRL, EBS = 0) 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)	Ensure high-quality insurance coverage
	Affordable insurance coverage	...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) 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) 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) 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)	Insurance coverage or financial support to promote accessibility to physical activity
	Insurance coverage for and access to lymphedema treatment	I can't buy—can't afford... I just can get the one. I say every 6 mo, yeah, you should at least be able to purchase another one. (Meredith, age 68 y, +BCRL) My insurance didn't cover the garment, and, you know, the sleeve, and the wrappings, ...and that was, like, \$300 and some ...And then I had to buy the bandages, the tape to go with the bandages... \$95 for the bandages, and then the tape that you buy to wrap the bandages, the Ace, that runs to, like, \$5 dollars a roll for the tape, you know... Sad to say, I don't follow through with it. I haven't followed through. (Phyllis, age 73 y, +BCRL, EBS = 2)	Keep co-pays, premiums and deductibles low Expand coverage for lymphedema-specific materials

TABLE 2. *Continued*

Domain	Specific Focus	Representative Quote (Age, Lymphedema Status, and Economic Burden Score When Available) ^a	Specific Recommendation
		The problem is with the Medicare and the secondary insurance... They only pay for X amount of [physical therapy] visits, so once you use them up, you can't go back. You have to wait 'til the next year. (Phyllis, age 73 y, +BCRL, EBS = 2)	Expand coverage for long-term lymphedema management
		So I went to a [physical] therapist, who at that time ...was all out of pocket. And it was significant. I went months and months... I was seeing her 3 times a week initially...during the first, I would say, 5, 6 y after my cancer diagnosis. It was a lot of out-of-pocket expense, which was not covered by insurance... It would have been helpful if insurance had paid some of that. (Rosemary, age 67 y, +BCRL, EBS = 0)	
		So I had used acupuncture in the past, so I did go to Doctor ____ for acupuncture...after 3 treatments, the fluid did go down in the hand... I believe in integrative medicine, and complementary medicine... Eastern and Western. (Rosemary, age 67 y, +BCRL, EBS = 0)	Expand insurance coverage for alternative treatments

Abbreviations: ACA, the Patient Protection and Affordable Care Act; +BCRL, diagnosed with breast cancer-related lymphedema; -BCRL, no history of breast cancer-related lymphedema; COBRA, The Consolidated Omnibus Budget Reconciliation Act of 1985 (an insurance program that gives some employees the ability to continue health insurance coverage after leaving); EBS, economic burden score; MRI, magnetic resonance imaging.

^aTo protect the confidentiality of study participants, pseudonyms are used in reporting the results.

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 benefitted 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

TABLE 3. Patient-Driven Recommendations for Offering Supportive Care and Services After Breast Cancer

Domain	Specific Focus	Representative Quote (Age, Lymphedema Status, and Economic Burden Score, When Available) ^a	Specific Recommendation
Supportive care and services	Support groups/buddy system	<p>...There was not a support group at that oncology practice at that time, until after I completed treatment. I did go to a couple of support group meetings after the fact. It was difficult, because a lot of the women at the meetings I attended had gone through chemo at the same time, so they had a bond, and I was trying to become a part of that and that was a little—that was difficult. And I also did not—I mean, there were some sexual issues that I wanted to talk about and did not feel comfortable in bringing the subject up when the moderator was male. (Geraldine, age 59 y, -BCRL, EBS = 0)</p> <p>...They do have support groups, but I remember thinking at the time, it may have been nice to just have a buddy...having more 1-on-1 interaction with someone that had been through more of something similar to me... I guess, just to be able to listen to the... the fears and the anxieties, and shed some light on, you know... being able to get through that and get to the other side, and... a sounding board. (Iris, age 52 y, +BCRL, EBS = 1)</p> <p>There needs to be some sort of a woman-to-woman pal-type thing...that sees your doctor, that goes with you to the biopsy, that runs with you to those things. Your husband is crazed. You know, he's hearing the same thing you are, and he's getting hit between the eyes, you know? And I just think that you need a cancer pal. (Jill, age 73 y, -BCRL, EBS = 7)</p>	One-on-1 buddy or "cancer pal" system for support
	Home care after cancer	<p>I was doing everything I thought I was supposed to, but then I was going to get reconstruction, and I ended up with a really, really bad infection. They sent me home with these drains, and I guess I obviously didn't do it well enough. I wish there had been home care for me. (Emma, age 57 y, +BCRL, EBS = 3)</p> <p>So what is available for you? What resources are there? And so I had a nurse. She'd come in the morning, but she was coming to change the wound. She was only there for a few minutes. But after that... I needed to take a shower or a bath. (Mary, age 69 y, -BCRL, EBS = 11)</p>	Expand availability of home care services
	Transportation	<p>... Of course you can't drive, so you need someone to transport you to any kind of visit that you need. (Jean, age 56 y, +BCRL, EBS = 0)</p> <p>So I'm like, what's available for cancer patients? What can you get? Just a ride to the hospital. You know, I had to drive myself to the hospital and I just, some days, you—some days you didn't—I mean, it was like, you didn't even feel like getting out of the bed. (Mary, age 69 y, -BCRL, EBS = 11)</p>	Create or leverage community-based ride-sharing programs designed for those with disabilities or illnesses
	Domestic assistance	<p>So, helping out around your house, housekeeping, or preparing meals, things like that. (Jean, age 56 y, +BCRL, EBS = 0)</p> <p>I could have used a home assistant, where someone comes in and helps in the [household chores]. (Mary, age 69 y, -BCRL, EBS = 11)</p>	Provide domestic help for household chores
	Childcare	<p>Well, childcare—when I had my surgery, I couldn't move my arm for a while. (Jean, age 56 y, +BCRL, EBS = 0)</p> <p>It was really rough, so I had to send my children to stay with my son because I couldn't afford to really take care of them and just do the best that I could. (Nellie, age 60 y, +BCRL, EBS = 9)</p>	Provide domestic help for childcare

Abbreviations: +BCRL, diagnosed with breast cancer-related lymphedema; -BCRL, no history of breast cancer related-lymphedema; EBS, economic burden score.

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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,

TABLE 4. Patient-Driven Recommendations for Potential Financial Assistance to Reduce Out-of-Pocket Cost Burden after Breast Cancer

Domain	Specific Focus	Representative Quote (Age, Lymphedema Status, and Economic Burden Score, When Available) ^a	Specific Recommendation
Financial assistance	Financial services for those above the poverty line	I went to apply for public assistance, and they said that I had “made too much money that year: come back next year.” And I said, “I might not be here next year.” And they’re like, “Okay, well, you know, you have to come back.” I couldn’t... I said, “I don’t want the money: can I get the medical?” And they were like, “No, come back in a year.” I just wanted medical, because that would help me with the, you know, the chemo drugs and stuff. (Nellie, age 60 y, +BCRL, EBS = 9) I think there are things in place for people who are very financially needy, but not really for someone who is like... I don’t know what kind of classification I am, but who can still work, who doesn’t want to work, but if I would stop working, would be very financially needy. (Diane, age 70 y, –BCRL)	Expand eligibility for financial aid and social services to those who are not in poverty
	Raising awareness of existing services	And when I found out what [services] was available, I utilized it. But, why do you have to go through that? Why isn’t there a service at the hospital that they can provide to cancer patients, these are the services that you can pick up the phone and call. (Mary, age 69 y, –BCRL, EBS = 11)	Provide a point of contact or informational pamphlets in oncologists’ offices regarding existing services or potential challenges
	Financial counseling/planning	I would hope that, when you would get referred or get that first diagnosis; so, in the doctor’s offices, it would be great to have someone when you go see the doctor to say, “Listen, we want you to see our resource person to see if we can help you with any type of challenges that you may face. Maybe these aren’t your challenges but, in fact, if you have them, here.” In later years, I found out there were programs that would have helped you pay rent, help you do this, help you do that. (Nellie, age 60 y, +BCRL, EBS = 9) Maybe trying to counsel women who are in a financial situation that are refusing treatment because they can’t afford it and, so, they just deny that they have anything wrong. (Emma, age 57 y, +BCRL, EBS = 3) I guess asking for help, asking for a financial planner or something like that; I guess being more aware, yeah, being more aware of what credit card debt does between the compound interest and things like that. (Ann, age 64 y, +BCRL, EBS = 5)	Offer referrals to resource navigator Connect patients or offer services to provide financial counseling throughout the diagnosis and treatment process

Abbreviations: +BCRL, diagnosed with breast cancer-related lymphedema; –BCRL, no history of breast cancer related-lymphedema; EBS, economic burden score.
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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.

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) ^a	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... I don't know what happens 6 mo or more, but for these illnesses, like cancer and some others that may be the same magnitude, I think people need more than just 3 mo, you know, to come back, to be able to get themselves together. (Cheryl, 52 y, -BCRL, EBS = 7) 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. (Alice, age 65 y, +BCRL)	Expansion of time covered by FMLA beyond 12 wk

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.

^aTo protect the confidentiality of study participants, pseudonyms are used in reporting the results.

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.³⁵ 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.⁴² 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.

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,⁴³ 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.⁴⁴ 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.⁴⁵ 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,⁴⁶ 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.⁴⁷ 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.⁴⁸ 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.⁴⁹

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,⁵⁰ 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.⁵¹⁻⁵³ 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.^{30,51,52} 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.^{54,55}

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.⁵⁶ 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.⁵⁷ 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.³⁹ 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.⁵⁸ Without lowering financial burden, making individual patients aware of the costs still puts a premium on

health³⁹ 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.⁴⁴ 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.⁵⁹ 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,⁶⁰ 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 burdensome 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.

FUNDING SUPPORT

This work was supported by the National Cancer Institute (grant K01CA184288 to Lorraine T. Dean), the National Institute of Mental Health (R25MH083620 to Lorraine T. Dean), the Johns Hopkins University Center for AIDS Research (grant P30AI094189 to Lorraine T. Dean, Sarah I. Rollinson, and Livia Frasso Jaramillo), the Sidney Kimmel Cancer Center (grant P30CA006973 to Lorraine T. Dean, Sarah I. Rollinson, and Livia Frasso Jaramillo), and the National Institute on Drug Abuse (grant T32DA031099 to Shadiya L. Moss).

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.

REFERENCES

1. American Cancer Society. Cancer Treatment and Survivorship Facts and Figures 2016-2017. Atlanta, GA: American Cancer Society; 2016.
2. Rosenberg PS, Barker KA, Anderson WF. Estrogen receptor status and the future burden of invasive and in situ breast cancers in the United States [serial online]. *J Natl Cancer Inst.* 2015;107:djv159.
3. Smith BD, Smith GL, Hurria A, Hortobagyi GN, Buchholz TA. Future of cancer incidence in the United States: burdens upon an aging, changing nation. *J Clin Oncol.* 2009;27:2758-2765.
4. Davidoff AJ, Erten M, Shaffer T, et al. Out-of-pocket health care expenditure burden for Medicare beneficiaries with cancer. *Cancer.* 2013;119:1257-1265.
5. Guy GP Jr, Yabroff KR, Ekwueme DU, et al. Healthcare expenditure burden among non-elderly cancer survivors, 2008-2012. *Am J Prev Med.* 2015;49(6 suppl 5):S489-S497.
6. Ramsey SD, Bansal A, Fedorenko CR, et al. Financial insolvency as a risk factor for early mortality among patients with cancer. *J Clin Oncol.* 2016;34:980-986.
7. Altice CK, Banegas MP, Tucker-Seeley RD, Yabroff KR. Financial hardships experienced by cancer survivors: a systematic review [serial online]. *J Natl Cancer Inst.* 2017;109:djw205.
8. Yabroff KR, Dowling EC, Guy GP Jr, et al. Financial hardship associated with cancer in the United States: findings from a population-based sample of adult cancer survivors. *J Clin Oncol.* 2016;34:259-267.
9. Bennett CL, Calhoun EA. Evaluating the total costs of chemotherapy-induced febrile neutropenia: results from a pilot study with community oncology cancer patients. *Oncologist.* 2007;12:478-483.
10. Bilir SP, Ma Q, Zhao Z, Wehler E, Munakata J, Barber B. Economic burden of toxicities associated with treating metastatic melanoma in the United States. *Am Health Drug Benefits.* 2016;9:203-213.
11. Irwin DE, Masaquel A, Johnston S, Barnett B. Adverse event-related costs for systemic metastatic breast cancer treatment among female Medicaid beneficiaries. *J Med Econ.* 2016;19:1027-1033.
12. Hansen RN, Ramsey SD, Lalla D, et al. Identification and cost of adverse events in metastatic breast cancer in taxane and capecitabine based regimens [serial online]. *Springerplus.* 2014;3:259.
13. Hurvitz S, Guerin A, Brammer M, et al. Investigation of adverse-event-related costs for patients with metastatic breast cancer in a real-world setting. *Oncologist.* 2014;19:901-908.
14. Rashid N, Koh HA, Baca HC, Lin KJ, Malecha SE, Masaquel A. Economic burden related to chemotherapy-related adverse events in patients with metastatic breast cancer in an integrated health care system [serial online]. *Breast Cancer (Dove Med Press).* 2016;8:173-181.
15. Shih YC, Xu Y, Cormier JN, et al. Incidence, treatment costs, and complications of lymphedema after breast cancer among women of working age: a 2-year follow-up study. *J Clin Oncol.* 2009;27:2007-2014.
16. Schmitz KH, DiSipio T, Gordon LG, Hayes SC. Adverse breast cancer treatment effects: the economic case for making rehabilitative programs standard of care. *Support Care Cancer.* 2015;23:1807-1817.
17. Norman SA, Localio AR, Potashnik SL, et al. Lymphedema in breast cancer survivors: incidence, degree, time course, treatment, and symptoms. *J Clin Oncol.* 2009;27:390-397.
18. Paskett ED. Symptoms: lymphedema. In: Ganz PA, ed. *Improving Outcomes for Breast Cancer Survivors.* Cham, Switzerland: Springer International Publishing AG; 2015:101-113.
19. Dean LT, Moss SL, Ransome Y, et al. "It still affects our economic situation": long-term economic burden of breast cancer and lymphedema [published online ahead of print August 18, 2018]. *Support Care Cancer.* doi: <https://doi.org/10.1007/s00520-018-4418-4>.
20. Bernard DS, Farr SL, Fang Z. National estimates of out-of-pocket health care expenditure burdens among nonelderly adults with cancer: 2001 to 2008. *J Clin Oncol.* 2011;29:2821-2826.

21. Zafar SY, Peppercorn JM, Schrag D, et al. The financial toxicity of cancer treatment: a pilot study assessing out-of-pocket expenses and the insured cancer patient's experience. *Oncologist*. 2013;18:381-390.
22. Arozullah AM, Calhoun EA, Wolf M, et al. The Financial burden of cancer: estimates from a study of insured women with breast cancer. *J Support Oncol*. 2004;2:271-278.
23. Banegas MP, Guy GP Jr, de Moor JS, et al. For working-age cancer survivors, medical debt and bankruptcy create financial hardships. *Health Aff (Millwood)*. 2016;35:54-61.
24. Carrera PM, Kantarjian HM, Blinder VS. The financial burden and distress of patients with cancer: understanding and stepping-up action on the financial toxicity of cancer treatment. *CA Cancer J Clin*. 2018;68:153-165.
25. Narang AK, Nicholas LH. Out-of-pocket spending and financial burden among Medicare beneficiaries with cancer. *JAMA Oncol*. 2016;3:757-765.
26. Dupas P. Health behavior in developing countries. *Annu Rev Econ*. 2011;3:425-449.
27. Timmons A, Gooberman-Hill R, Sharp L. The multidimensional nature of the financial and economic burden of a cancer diagnosis on patients and their families: qualitative findings from a country with a mixed public-private healthcare system. *Support Care Cancer*. 2013;21:107-117.
28. Timmons A, Gooberman-Hill R, Sharp L. "It's at a time in your life when you are most vulnerable": a qualitative exploration of the financial impact of a cancer diagnosis and implications for financial protection in health [serial online]. *PLoS One*. 2013;8:e77549.
29. Sharp L, Timmons A. Pre-diagnosis employment status and financial circumstances predict cancer-related financial stress and strain among breast and prostate cancer survivors. *Support Care Cancer*. 2016;24:699-709.
30. Zafar SY, Newcomer LN, Jusfin McCarthy J, Nasso SF, Saltz LB. How should we intervene on the financial toxicity of cancer care? One shot, 4 perspectives. *Am Soc Clin Oncol Educ Book*. 2017;37:35-39.
31. Zafar SY. Financial toxicity of cancer care: it's time to intervene [serial online]. *J Natl Cancer Inst*. 2016;108:djv370.
32. Institute of Medicine and National Research Council. *From Cancer Patient to Cancer Survivor: Lost in Transition*. Washington, DC: The National Academies Press; 2006.
33. Spencer JC, Samuel CA, Rosenstein DL, et al. Oncology navigators' perceptions of cancer-related financial burden and financial assistance resources. *Support Care Cancer*. 2018;26:1315-1321.
34. Brown ML, Yabroff KR. Chapter 12: economic impact of cancer in the United States. In: Schottenfeld D, Fraumeni JF Jr, eds. *Cancer Epidemiology and Prevention*. 3rd ed. New York: Oxford University Press, 2006:202-216.
35. Pisu M, Martin MY, Shewchuk R, Meneses K. Dealing with the financial burden of cancer: perspectives of older breast cancer survivors. *Support Care Cancer*. 2014;22:3045-3052.
36. Schmitz KH, Ahmed RL, Troxel AB, et al. Weight lifting for women at risk for breast cancer-related lymphedema: a randomized trial. *JAMA*. 2010;304:2699-2705.
37. Schmitz KH, Troxel AB, Chevillat A, et al. Physical Activity and Lymphedema (the PAL trial): assessing the safety of progressive strength training in breast cancer survivors. *Contemp Clin Trials*. 2009;30:233-245.
38. Patterson RE, Colditz GA, Hu FB, et al. The 2011-2016 Transdisciplinary Research on Energetics and Cancer (TREC) initiative: rationale and design. *Cancer Causes Control*. 2013;24:695-704.
39. Dean LT, Schmitz KH, Frick KD, et al. Consumer credit as a novel marker for economic burden and health after cancer in a diverse population of breast cancer survivors in the USA. *J Cancer Surviv*. 2018;12:306-315.
40. Gordon L, Scuffham P, Hayes S, Newman B. Exploring the economic impact of breast cancers during the 18 months following diagnosis. *Psychooncology*. 2007;16:1130-1139.
41. Given BA, Given CW, Stommel M. Family and out of pocket costs for women with breast cancer. *Cancer Pract*. 1994;2:187-193.
42. Dean LT, Moss SL, McCarthy AM, Armstrong K. Healthcare system distrust, physician trust, and patient discordance with adjuvant breast cancer treatment recommendations. *Cancer Epidemiol Biomarkers Prev*. 2017;26:745-752.
43. Head B, Harris L, Kayser K, Martin A, Smith L. As if the disease was not enough: coping with the financial consequences of cancer. *Support Care Cancer*. 2018;26:975-987.
44. Nipp RD, Sonet EM, Guy GP. Jr Communicating the financial burden of treatment with patients. *Am Soc Clin Oncol Educ Book*. 2018;38:524-531.
45. Boyages J, Xu Y, Kalfa S, et al. Financial cost of lymphedema borne by women with breast cancer. *Psychooncology*. 2017;26:849-855.
46. Moy B, Polite BN, Halpern MT, et al. American Society of Clinical Oncology policy statement: opportunities in the patient protection and affordable care act to reduce cancer care disparities. *J Clin Oncol*. 2011;29:3816-3824.
47. Fu MR, Ridner SH, Hu SH, Stewart BR, Cormier JN, Armer JM. Psychosocial impact of lymphedema: a systematic review of literature from 2004 to 2011. *Psychooncology*. 2013;22:1466-1484.
48. Weiss R. Cost of a lymphedema treatment mandate-10 years of experience in the Commonwealth of Virginia [serial online]. *Health Econ Rev*. 2016;6:42.
49. Abdelsattar ZM, Hendren S, Wong SL. The impact of health insurance on cancer care in disadvantaged communities. *Cancer*. 2017;123:1219-1227.
50. Subramani R, Lakshmanaswamy R. *Complementary and alternative medicine and breast cancer*. In: *Progress in Molecular Biology and Translational Science*. Elsevier; 2017:231-274.
51. Wang B, Joffe S, Kesselheim AS. Chemotherapy parity laws: a remedy for high drug costs? *JAMA Intern Med*. 2014;174:1721-1722.
52. Dusetzina SB, Huskamp HA, Winn AN, Basch E, Keating NL. Out-of-pocket and health care spending changes for patients using orally administered anticancer therapy after adoption of state parity laws [serial online]. *JAMA Oncol*. 2018;4:e173598.
53. Skopec L. ACS CAN Examination of Cancer Drug Coverage and Transparency in the Health Insurance Marketplaces. Washington, DC: American Cancer Society Cancer Action Network; 2015.
54. Mukherjee S. Lyft is offering free rides to cancer patients in major US cities. *Fortune*. June 21, 2018.
55. Herper M. At Joe Biden's urging, Airbnb, WeWork, and others commit to help cancer patients. *Forbes*. September 21, 2018.
56. Burckhardt M, Belzner M, Berg A, Fleischer S. Living with breast cancer-related lymphedema: a synthesis of qualitative research. *Oncol Nurs Forum*. 2014;41:E220-E237.
57. Khera N, Holland JC, Griffin JM. Setting the stage for universal financial distress screening in routine cancer care. *Cancer*. 2017;123:4092-4096.
58. Shankaran V, Leahy T, Steelquist J, et al. Pilot feasibility study of an oncology financial navigation program. *J Oncol Pract*. 2017;14:e122-e129.
59. US Department of Labor, Wage and Hour Division. Fact Sheet 28: The Family and Medical Leave Act. Washington, DC: US Department of Labor; 2012; Available at: <https://www.dol.gov/whd/regs/compliance/whdfs28.pdf>. Accessed June 5, 2018.
60. Sun Y, Shigaki CI, Armer JM. Return to work among breast cancer survivors: A literature review. *Supportive Care in Cancer*. 2017;25:709-718.