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

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Abstract

Background—In the United States, breast cancer patients experience significant economic burden, even compared to other cancer patients. Cancer-related economic burden is exacerbated by adverse treatment effects. Strategies to resolve economic burden due to breast cancer and its adverse treatment effects have stemmed from the perspectives of healthcare providers, oncology navigators, and other subject matter experts. This study elicited patient-driven recommendations to reduce economic burden after (1) breast cancer, and (2) breast cancer-related lymphedema, a common persistent adverse effect of breast cancer.

Methods—We conducted qualitative interviews of 40 long-term breast cancer survivors who were Pennsylvania or New Jersey residents in 2015 and enrolled in a 6-month observational study. Purposive sampling ensured equal representation by age, socioeconomic position, and lymphedema diagnosis. Semi-structured interviews addressed economic challenges, supports utilized, 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.

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

Conclusion—This study provides nine actionable patient-driven recommendations – changes to insurance, supportive services, financial assistance, and protective policies – to reduce breast cancer related economic burden. Recommendations should be tested through policy and programmatic interventions.

PRECIS

This paper offers nine actionable patient-driven recommendations for reducing economic burden after breast cancer. Recommendations address changes to insurance, supportive services, financial assistance, and protective policies that can reduce economic burden after cancer.

Keywords

lymphedema; economic burden; breast cancer; qualitative analysis; United States

BACKGROUND

There are currently an estimated 3.1 million breast cancer survivors in the United States (US)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 mortality³. 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 effects¹. In the US, breast cancer patients experience significant economic burden, even compared to other cancer patients^{4–8}. Economic burden after cancer may be further exacerbated for patients managing adverse treatment effects^{9–14}, such as breast cancer-related lymphedema^{15,16}. Breast cancer-related lymphedema is one of the most common and costly breast cancer related adverse treatment effects, affecting nearly 35% of breast cancer survivors in the US^{17,18} and resulting in an estimated \$14,877 in out-of-pocket costs in the first two years of a diagnosis¹⁵. Even up to 10 years after diagnosis, out-of-pocket health costs for those with breast-cancer related are over double those without breast cancer-related lymphedema¹⁹. 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 with lymphedema because many public insurance plans do not cover compression bandages or garments for self-management of lymphedema²⁶. Those with limited resources or few financial reserves may experience the most challenges after diagnosis^{27–29}.

Studies documenting the impact of economic burden on cancer survivors have explored provider-driven recommendations^{30–32} and oncology navigator perceptions³³ for reducing economic burden. Provider-driven recommendations largely focus on addressing elements of

the healthcare system and direct medical costs^{30–32}, such as payments made for health needs by the patient or insurer. Yet, economic burden, from a patient perspective 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 non-medical direct costs, such as transportation to medical visits³⁴. 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 burden³⁵. However, the study only included older breast cancer survivors from one safety-net clinic; therefore, an assessment of breast cancer survivors across age groups, insurance, and healthcare systems might yield new or different findings.

The purpose of this study is 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.

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 of the Physical Activity and Lymphedema (PAL) trial (n=295)^{37, 38} who were still alive, or participants who were ineligible (n=163) for the ongoing Women in Steady Exercise Research (WISER) Survivor Study ([ClinicalTrials.gov #NCT01515124](https://clinicaltrials.gov/ct2/show/study/NCT01515124))³⁹, but met requirements for entry into PAL to ensure 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-III invasive breast cancer; completion of active breast cancer treatment; >1 lymph node removed, and current residents of Pennsylvania or New Jersey. Additional details of study recruitment have been previously published³⁶. A total of 129 women enrolled in the study, and 40 of these women were selected for a qualitative interview. Purposive sampling was employed to ensure equal representation across lymphedema status, age group (over 65 and under 65), 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 the study. Written informed consent was obtained from each individual participant.

Data Collection

At baseline, participants completed a demographic and health history survey, including 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 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 semi-structured interview guide (Appendix 1), which addressed economic challenges, supports utilized, 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 MAXQDA software program. MAXQDA is a data analysis software 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 the systematic coding and comparison of the text. First, structural codes were identified based on the relevant economic burden domains previously identified in the research literature³⁴. 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 due to 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 two analysts. Discrepancies were discussed and resolved among the research team. Lastly, 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

Table 1 descriptive statistics were based on 40 interviewees. Mean age of interviewees was 64 years. Less than half were Black (42.5%), slightly more than half (53%) were White, the remaining 5% identified as another race. Most (53%) were college graduates or received graduate degrees. Approximately 11% had an income less than \$30,000, and plurality had an income of \$30,000-\$70,000 (58%); household income supported two people on average. More than 1/3 had total cash assets totaling less than \$5,000 (35.1%), with 27% each totaling \$5,000-\$49,999 or \$50,000-\$499,999. The remaining 11% had cash assets greater than \$500,000. 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, with the vast majority having private insurance (82.5%). Approximately 62% were diagnosed at Stages 0 or 1, with 39% diagnosed at Stages 2 or 3. The remaining 23% were missing information on Stage at diagnosis and could not be categorized. The mean years since diagnosis was 12. The majority received chemotherapy (77%) and radiation (83%), with a quarter also undergoing hormonal therapy (25%). Participants had a mean of 2 comorbidities. Over half of the women (60%) experienced breast-cancer related lymphedema.

QUALITATIVE FINDINGS

Of the total 40 interviews, ten did not offer any recommendations, and three 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 four major areas for improvement: insurance, supportive services and care, financial assistance, and protective policies. Patients offered nine specific recommendations across the four domains. Tables 2–5 show representative quotes of challenges patients experienced and suggestions for change.

Insurance (Table 2)—Women in our study with and without breast cancer-related lymphedema felt it was challenging to navigate the insurance system and would have benefitted from a navigator to explain the process to them. Frances' (age 56, no lymphedema) quotation illustrates how although using insurance should be cost saving, it can actually cost a patient time and money, and contribute to anxiety out of a sense of not knowing what will happen. The quotation highlights the gap between what patients need and what insurance companies are willing to cover without additional effort by the patient. As noted by Elizabeth (age 55, no lymphedema), having stable employment and income is critical to obtaining necessary cancer-related treatments that are not covered by insurance. Her comment reflects 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 in order to afford those non-covered items. Participants emphasized that having quality insurance, which 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 getting supplies for lymphedema self-management paid for by insurance. Garments, tape, and bandages must be replaced several times a year, posing ongoing lifetime costs that accumulate. Phyllis (age 74, 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, were generally not covered by insurance, but should be.

Specific recommendations for insurance included:

1. Provide assistance with understanding what is covered under insurance and how to navigate changes when switching to a new insurance provider.
2. Ensure high-quality insurance that covers required and elective cancer-related services, low co-pays, premiums and deductibles.
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 (Table 3)—The most commonly mentioned suggestion was psychosocial support to reduce psychosocial costs of stress and anxiety. Patients mentioned support groups as a way to connect with other women to seek recommendations about treatments, hospitals, and services they could use post-diagnosis. Among those who did not use support groups, common problems were: not available locally and long distances needed to travel; feeling like the information needed to be more tailored to their specific health needs, or simply not knowing where to find them 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 breast cancer patients in our study without lymphedema, exercise was identified in improving feelings of well-being. Patients would benefit from exercise regimens; however, these 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 guidelines post-surgery and reconstruction severely restrict movement. Furthermore, post-surgery care guidelines can be overwhelming and lead to confusion and side effects. Emma (age 57, has lymphedema), discussed how lack of home healthcare for surgical drains led to an infection. These challenges were present even though she lived with other people.

Specific recommendations for supportive services and care included:

4. Address psychosocial costs by expanding support groups and buddy services.
5. Expand availability of home healthcare services after cancer treatment.
6. Provide domestic assistance with household chores, childcare, and transportation.

Financial Assistance (Table 4)—Women also identified a lack of programs, or knowledge of programs, designed to financially assist women above the poverty line. Interviewees felt as though the process to find 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 non-profit 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. As patients suggest, screening and referral to financial services could occur during or near oncology visits and be given 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 if they do find themselves facing a new challenge, they would already have a point of reference to seek assistance.

Specific recommendations related to financial assistance included:

7. Expand eligibility for financial aid and social services to those who are not in poverty.
8. Provide financial counseling or navigation throughout the diagnosis and treatment process.

Protective Policies (Table 5)—Both women with and without lymphedema identified concerns about uncertainty regarding employment following their breast cancer treatment in the US. 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, cancer patients can be subject to individual company policy, 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 of the US. 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 FMLA, and greater protections to return to one's employment without penalty.

The specific recommendation for protective policies was:

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 support³⁵. Additionally, our 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 what treatments insurance cover as standard. Patients want existing structures improved, which may decrease healthcare system distrust⁴². Overall, patients want protection from the cascade of economic burden, and full protection would require

additional insurance coverage and services for those managing a long-term adverse treatment effect such as 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 one entity that can resolve the challenge of high out-of-pocket costs for breast cancer survivors. While 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 see how their interests in changing various elements involved in healthcare delivery might interact or conflict. Still, patients live the reality of healthcare delivery, and their thoughts on how it can be improved adds value to decision-making processes.

Insurance

Patients consistently pointed to a need for help with insurance navigation, though they did not identify who should provide this service. Navigating insurance systems requires problem-focused coping skills⁴³ that have both time and psychosocial costs. The cost to overcome these challenges may be too overwhelming for cancer patients 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 hospital⁴⁴. 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 lowest economic burden believed it was due to having “good insurance.” Patients incur substantial out-of-pocket costs that they may not know could be covered by insurance, or may not be covered by insurance⁴⁵. This was especially true among those with lymphedema which, despite the Affordable Care Act’s success in expanding affordable insurance coverage for cancer-related care⁴⁶, did not address adverse treatment effects of cancer. Studies prior to the 2010 Affordable Care Act reported that financial burden created worry and anger when tools for lymphedema management were not covered by insurance⁴⁷. Our findings suggest insurance expansion for cancer has not filled the insurance gap for patients with lymphedema; however, some states have designed legislation to address lymphedema specifically. A study in one state showed 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 years⁴⁸. 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 US Congressional level. To reduce economic burden after cancer, those 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 coverage⁴⁹.

Patients suggested expanded coverage for complementary and integrative medicines. Subramani, et al found that the majority of cancer patients did not receive instruction about it from their physician⁵⁰, which our study corroborates. Both expanded insurance coverage and physician education could increase the awareness and use of complementary and integrative medicines among cancer patients.

While 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 anti-cancer medications⁵¹⁻⁵³. Subsequently, several states have considered or passed bills that limit patient cost-sharing, which shows 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 healthcare 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 non-medical services and instrumental support can help reduce financial, psychosocial, and time costs. Existing programs that currently provide home healthcare 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 non-profits 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 patient who recently completed cancer treatment. This expansion could offer additional help with household chores and childcare. Existing transportation infrastructure (e.g., 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 lymphedema patients, who may have less ability to perform activities of daily living during lymphedema bouts^{54, 56}. Changes to these support systems would likely 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 treatment⁵⁷. 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 such as 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 best benefit from an intervention³⁶. Charitable assistance organizations or state financial assistance programs could re-consider whether their guidelines should be based on the federal poverty guidelines, or increase the flexibility of their eligibility requirement in response to unique situations.

Financial navigation has been previously suggested by healthcare providers, and this study suggests 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, though self-reported financial burden did not substantially change⁵⁸. Without lowering financial burden, making individual patients aware of the costs still puts a premium on health³⁶, and may exacerbate disparities since those with the greatest resources will be able to afford better health services. Our findings align with other recent findings of patient's desire for physicians to have some of these conversations, though clinician's have expressed concerns about appropriateness, ability to supply accurate information, and time barriers⁴⁴. While 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; thus automatic referral by the physician or other 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 Family and Medical Leave Act (FMLA) and short-term disability. In the US, FMLA allows eligible employees to take up to 12 workweeks of unpaid continuous or intermittent leave in a 12-month period (or up to 26 weeks for an eligible military servicemember). After returning from leave the "employee must be restored to his or her 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. While FMLA is a step towards preserving employment, participants suggest that it needs to be expanded, especially given that active cancer treatment and associated recovery may take 6 months or more. Expanding FMLA would require action by the US Congress and the US Department of Labor, though some states have enacted more expansive FMLA regulations.

Patients who can access FMLA and short-term disability programs concurrently may be in the best position to navigate economic shocks due to cancer, but it is unclear how many people are dually eligible. Financial counseling that addresses options for FMLA, short-term and long-term disability may be warranted. Redesigning sick leave policies to better accommodate chronic disease needs has been previously suggested⁶⁰, and this analysis supports the finding that patients perceive that changes to these programs would reduce economic burden after cancer.

Limitations—All participants were from the East Coast and currently insured, with low overall economic burden. Responses may be different from women living in regions with other insurance offerings. As a voluntary research study, those experiencing the greatest economic challenges may not have had time to enroll and participate, meaning that our results may underestimate the economic burden. Results may not be generalizable to other tumor sites, but breast cancer is among the most economically burdensome cancers. No participants were in active cancer treatment. 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 inferred (e.g., changes in 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 this United States. This qualitative study adds to the literature by representing the patient perspective on reducing economic burden after breast cancer, and providing nine 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. Recommendations are actionable, and should be further explored in testable policy and programmatic interventions. Future studies might consider comparative viewpoints of these recommendations from various members of the healthcare, insurance, and policy-making communities.

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APPENDIX I: PAL SEQL Qualitative Interview – 6 Month Measurement Visit

Date: _____ Study ID_____

Interviewer:

Interviewer: The PAL Social and Economic Quality of Life (PAL SEQL) Research Study recognizes that the information from the surveys we collect do not always capture the complexities of life. In order to better understand economic challenges you might have faced since your cancer diagnosis, we would like to interview you about your personal experiences. May we record this interview so that we can review your comments later? Please remember, that even if we record, we do not use your actual voice, and the recording is so that we can transcribe what you say into our notes. If we do use a direct quote from you, we will not use your name or identify you as person giving the quote. Your confidentiality and privacy will be protected at all times.

[Indicate Yes or No for allowing recording. Start recorder, if applicable, noting date, interviewer name, participant Study ID, and participant indication of allowing the recording.]

Thank you. My first question is...

1. What was the most significant economic challenge resulting from your cancer diagnosis?
 - a. How long ago was this?
 - b. How long after your cancer diagnosis did this happen?
 - c. For how long did this last?
 - d. On a scale of 0 to 5, with 0 being “not burdensome at all” and 5 being “extremely burdensome,” how would rate this experience?
2. What supports or resources were helpful to you to work through this challenge?
3. In what ways, if any, does this still affect you now?

Interviewer: Thank you for sharing. In order to help breast cancer survivors in the future, we would like to know what could help if others were to face this challenge.

4. What types of assistance could have helped you through this challenge or could have helped you to avoid this challenge?

Thank you for your time.

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Table 1.

Demographic Characteristics of Interviewees

N=40	N (%)
Demographics	
Age in years, Mean (SD)	64 (8)
Race	
Black	17 (42.5)
Other	2 (5)
White	21(52.5)
Education completed	
High school	19 (47.5)
College	12 (30)
Graduate school	9 (22.5)
Income	
\$30,000	4 (10.5)
\$30,001 - \$70,000	22 (57.8)
>\$70,000	12 (31.6)
Number of people income supports, M (SD)	2 (1)
Total cash assets	
\$4,999	12 (35.1)
\$5,000 - \$49,999	10 (27.0)
\$50,000 - \$499,999	10 (27.0)
500,000	4 (10.8)
Economic burden score, M (SD) [range: 0–12]	2.5 (4)
Insurance type *	
Public	12 (30)
Private	33 (82.5)
None	0
Clinical Variables	
Cancer stage at diagnosis	
Stage 0	10 (32.3)
Stage 1	9 (29.0)
Stage 2	7 (22.6)
Stage 3	5 (16.1)
Missing	9 (22.5)
Years since diagnosis, M (SD)	12 (5)
Radiation	33 (82.5)
Chemotherapy	30 (76.9)
Hormonal Therapy	10 (25)

N=40	N (%)
Comorbidities	2 (1)
Have lymphedema (+BCRL)	24 (60)

* Percentages sum to greater than 100% because participants could be simultaneously participating in public and private insurance plans

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Table 2. Patient-driven Recommendations for Improvement of Insurance System for Women with a History of Breast Cancer*

Domain	Specific Focus	Representative Quote (age, lymphedema status, 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, -BCRL, Economic Burden Score (EBS): 0]	Provide assistance understanding insurance coverage
		Yeah, I wish there was someplace that you could either go, or call, or whatever, that really understood how Medicare worked... [Jill, Age 73, -BCRL, EBS: 7]	
		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, poops [no more coverage for those items]. [Meredith, Age 68, +BCRL]	Provide assistance with navigating changes in insurance
		My COBRA had expired... I couldn't afford to pay a thousand dollars 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, +BCRL, EBS: 2]	
	Quality of insurance coverage	... they wanted me to have shots of Neupogen 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, \$1,500 apiece. [Eve, Age 59, -BCRL, EBS: 0]	Ensure high-quality insurance coverage
		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, +BCRL, EBS: 0]	
		... 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, -BCRL, EBS: 0]	Insurance coverage or financial support to promote accessibility to physical activity
	Affordable insurance coverage	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, -BCRL, EBS: 4]	Keep co-pays, premiums and deductibles low
		This year, for my daughter (20), and myself it is \$820/month for insurance with a \$6,000 deductible [Symbol] this year we got kicked out to the marketplace (ACA) and could have gone with a cheaper policy but I was afraid if I get sick, then what happens? [Frances, Age 56, -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 shot, and that shot was a hundred dollars 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, -BCRL, EBS: 0]	
	Insurance coverage for and access to lymphedema treatment	I can't buy-- can't afford. I just can get the one.. I say every six months, yeah, you should at least be able to purchase another one. [Meredith, Age 68, +BCRL]	Expand coverage for lymphedema-specific materials
		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, +BCRL, EBS: 2]	
		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, +BCRL, EBS: 2]	Expand coverage for long-term lymphedema management

Domain	Specific Focus	Representative Quote (age, lymphedema status, economic burden score when available)	Specific Recommendation
		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 three times a week initially...during the first, I would say five, six years 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, +BCRL, EBS: 0]	
		So I had used acupuncture in the past, so I did go to Doctor ** for acupuncture...after three treatments, the fluid did go down in the hand...I believe in integrative medicine, and complementary medicine... Eastern and Western [Rosemary, Age 67, +BCRL, EBS: 0]	Expand insurance coverage for alternative treatments

+BCRL=diagnosed with breast cancer-related lymphedema; -BCRL=no history of breast cancer related lymphedema; EBS=economic burden score

* To protect the confidentiality of study participants, pseudonyms are used in reporting the results.

Table 3. Patient-driven Recommendations for Offering Supportive Care and Services after Breast Cancer*

Domain	Specific Focus	Representative Quote	Specific Recommendation
Supportive Care and Services	Support groups/buddy system	...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, -BCRL, EBS: 0]	One-on-one buddy or "cancer pal" system for support
		...they do have support groups, but I remember thinking at the time, it may have been nice to just have a buddy...having more one-on-one 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... sounding board [Iris, Age 52, +BCRL, EBS: 1] There needs to be some sort of a woman-to-woman pal-type thing...that sees your doctor, that goes with you with 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, -BCRL, EBS: 7]	
	Home care after cancer	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, +BCRL, EBS: 3] 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, -BCRL, EBS: 11] ... of course you can't drive so you need someone to transport you to any kinda visit that you need. [Jean, Age 56, +BCRL, EBS: 0]	Expand availability of home care services
	Transportation		Create or leverage community-based ride-sharing programs designed for those with disabilities or illnesses
		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, -BCRL, EBS: 11] So helping out around your house, housekeeping or preparing meals, things like that. [Jean, Age 56, +BCRL, EBS: 0]	
	Domestic Assistance	I could have used a home assistance where someone come in and help in the [household chores]. [Mary, Age 69, -BCRL, EBS: 11]	Provide domestic help for household chores
	Childcare	Well, childcare-- well, when I had my surgery, I couldn't move my arm for a while. [Jean, Age 56, +BCRL, EBS: 0] it was really rough so I had to send my children to stay with my son 'cause I couldn't afford to really take care of them and just do the best that I could. [Nellie, Age 60, +BCRL, EBS: 9]	Provide domestic help for childcare

+BCRL=diagnosed with breast cancer-related lymphedema; -BCRL=no history of breast cancer related lymphedema; EBS=economic burden score

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Table 4. Patient-driven Recommendations for Potential Financial Assistance to Reduce Out-of-Pocket Cost Burden after Breast Cancer*

Domain	Specific Focus	Representative Quote	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 'cause that would help me with the, you know, the chemo drugs and stuff. [Nellie, Age 60, +BCRL, EBS: 9]	Expand eligibility for financial aid and social services to those who are not in poverty
		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, -BCRL]	
	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, -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 was programs that would have helped you pay rent, help you do this, help you do that. [Nellie, Age 60, +BCRL, EBS: 9]	Offer referrals to resource navigator
		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, +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, +BCRL, EBS: 5]	Connect patients or offer services to provide financial counseling throughout the diagnosis and treatment process

+BCRL=diagnosed with breast cancer-related lymphedema; -BCRL=no history of breast cancer related lymphedema; EBS=economic burden score

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Table 5. Patient-driven Recommendations for Improving Policies to Preserve Employment after Breast Cancer*

Domain	Specific Focus	Representative Quote	Specific Recommendation
Protective Policies	Policies protecting employment	The job I was working on terminated me and didn't inform me that I was terminated, 'cause I was out more than three months... I don't know what happens six months or more, but for these illnesses, like cancer and some others that may be the same magnitude, I think people need more than just three months, you know, to come back, to be able to get themselves together. [Cheryl, Age 52, -BCRL, EBS: 7]	Expansion of time covered by FMLA beyond 12 weeks
		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, +BCRL]	

+BCRL=diagnosed with breast cancer-related lymphedema; -BCRL=no history of breast cancer related lymphedema; EBS=economic burden score

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