

# The influence of breast cancer related lymphedema on women's return-to-work

Women's Health  
Volume 16: 1–16  
© The Author(s) 2020  
Article reuse guidelines:  
sagepub.com/journals-permissions  
DOI: 10.1177/1745506520905720  
journals.sagepub.com/home/whe



Yuanlu Sun<sup>1</sup> , Cheryl L Shigaki<sup>2</sup> and Jane M Armer<sup>3</sup>

## Abstract

**Background:** Lymphedema is one of the major treatment complications following breast cancer surgery and radiation. As the majority of women who develop breast cancer are at the age of employment, occupational functioning and employment are issues of concern. This study is novel in exploring the ways that lymphedema affects their work experience.

**Methods:** A multiple-case study methodology drawn from Yin's definition was employed. A total of 13 female survivors who developed breast cancer-related lymphedema participated by completing a survey and a 60-min semi-structured interview.

**Results:** Four main themes emerged: (1) breast cancer-related lymphedema affects physical and emotional functioning associated with work; (2) ongoing treatment for breast cancer-related lymphedema creates challenges for work; (3) environmental factors affect the return-to-work experience; and (4) personal factors play a key role in adjusting to return-to-work.

**Conclusion:** Both breast cancer-related lymphedema and its treatment have direct and indirect effects on work, with environmental and personal factors also shaping the work-return experience. This study suggests that breast cancer survivors with lymphedema who wish to return to work face potential barriers, and that gaps remain in the availability of supports.

## Keywords

breast cancer, lymphedema, occupational rehabilitation, return-to-work, survivorship

Date received: 14 May 2019; revised: 27 November 2019; accepted: 16 January 2020

## Introduction

Diagnosis and treatment of cancer have evolved in recent decades and, as a result, survival for persons with cancer continues to increase.<sup>1</sup> As of January 2016, there were approximately 15.5 million cancer survivors in the United States.<sup>2</sup> Breast cancer remains the second most common cancer affecting women in the United States, with a 5-year survival rate of 89.7%.<sup>3</sup>

More than 57% of women were diagnosed with breast cancer under the age of 64 years, which means the majority of women were in their employment age when undergoing breast cancer treatment.<sup>3</sup> Despite medical advancements in treatment, knowledge of the functional status of cancer survivors in daily life, including employment functioning, remains limited.<sup>4</sup> According to Feuerstein's et al.<sup>5</sup> review

on work among general cancer survivors, cancer treatment and diagnosis can lead to negative work outcomes (e.g. work return, ability, performance, and sustainability) and multiple factors could contribute to these outcomes (e.g. physical function, health/well-being, work demands, work environment, policy, and economic factors). Our recent

<sup>1</sup>College of Nursing, University of Missouri–St. Louis, St. Louis, MO, USA

<sup>2</sup>Health Psychology, Harry S. Truman Memorial Veterans' Hospital, Columbia, MO, USA

<sup>3</sup>Sinclair School of Nursing, University of Missouri, Columbia, MO, USA

### Corresponding author:

Yuanlu Sun, College of Nursing, University of Missouri–St. Louis, One University Boulevard, St. Louis, MO 63121-4400, USA.

Email: ys4k9@mail.missouri.edu; Sun\_Yuanlu@outlook.com



review on return-to-work among breast cancer survivors identified that personal factors, such as personality and coping, may also influence work-return outcomes.<sup>6</sup> Breast cancer survivors may deal with treatment-specific problems such as upper extremity impairment and lymphedema.<sup>6</sup> Because the majority of women who develop breast cancer are under the age of retirement, occupational functioning and employment are issues of significant concern for this population.

Lymphedema is one of the major treatment complications for breast cancer patients undergoing axillary lymph node dissection and radiation,<sup>7-9</sup> and it has become one of the greatest fears for survivors, second only to cancer recurrence.<sup>10</sup> In the Western world, between 20% and 40% of women treated for breast cancer experience lymphedema, which can occur at any time, from immediately after treatment onward.<sup>11,12</sup> Lymphedema occurs when protein-rich fluid accumulates in the extravascular interstitial spaces and leads to swelling of the affected body part, most often the extremities, but also neck, face, abdomen, trunk, and genitals.<sup>13</sup> The skin's protective layer may be reduced, leading to disruption of the body's natural immune defense system. Because the excess fluid contains proteins and accumulated waste products, even minor cuts can rapidly lead to severe infection, including erysipelas and septicemia. Damage to tissue and vessels may lead to localized inflammation and systemic symptoms of fever, chills, headache, and even vomiting. If severe, acute sickness caused by lymphedema-related infection may require hospitalization.<sup>13</sup>

To date, lymphedema cannot be completely cured or prevented. Complete decongestive therapy (CDT) is considered the "gold standard" of care for lymphedema, to reduce volume, control infection, manage fibrosis, and to improve functioning and overall quality of life.<sup>14</sup> CDT is a two-phase system comprising an intensive phase and a maintenance phase. The intensive phase consists of daily treatment including a type of massage referred to as manual lymph drainage (MLD), application of compression bandaging (typically 23-of-24-h a day, for up to 6 weeks), compression garments, remedial exercise, skincare, and education. Patients are typically required to visit therapists frequently during this interval. The maintenance phase focuses on a routine of self-management for lymphedema, in which survivors apply at home what they have learned in the intensive phase.<sup>14</sup>

Studies show that the detrimental effect of breast cancer related-lymphedema (BCRL) on women's work and career over and above the initial impact of breast cancer in the long term. Lymphedema may be associated with multiple adverse work outcomes such as decreased work productivity,<sup>15,16</sup> delay in returning to work,<sup>17</sup> reduced earnings,<sup>18</sup> unemployment,<sup>19,20</sup> more time off from work,<sup>16,18,19</sup> and reduced work capacity.<sup>15,18</sup> Despite the identified potential relationships between lymphedema and negative work

outcomes, there is almost no published research that investigates the precise reasons for the association. Without knowing how lymphedema influences breast cancer survivors' work experience, we cannot provide effective rehabilitation services to breast cancer survivors who need help with restoring and retaining occupational life. The aim of this study was to address this gap by investigating survivors' perspectives regarding the ways in which BCRL influences their work and by examining the contextual facilitators and barriers as survivors return-to-work.

The International Classification of Functioning, Disability, and Health (ICF)<sup>21</sup> was used as a framework for our inquiry. The ICF measures health and disability at both the individual and population levels. The ICF identifies three levels of the functions: the body, the person, and the environment, which contain three domains of human functions: (1) *body functions and structures* (the physiological functions and anatomical parts), (2) *activities* (execution of a task), and (3) *participation* (involvement in a life situation). Correspondingly, the decrement at each domain of the functions results in an impairment, an activity limitation, and a participant restriction. The unique contribution of the ICF lies in its recognition that health and disability do not occur in the absolute, a point that we wished to explore. The model displays the decreased function as the product of the interactions of the health conditions and the contextual (personal and environmental) factors. The ICF considers the relationships between the disease, function and disability, and acknowledges that they occur within specific contexts (e.g. age, education, social, and attitudinal environment).<sup>22</sup> The ICF has been employed in diverse population and been recommended to help understand the "return-to-work as a health behavior" among cancer survivors.<sup>23</sup>

## Methods

### Design

We used a multiple-case study design drawn from Yin's<sup>24</sup> definition, which referred to the inquiry about ongoing phenomenon within its real-life context, especially when the phenomenon (return-to-work with BCRL) and the context (e.g. environmental and personal factors) are not distinguishable. Based on Yin's<sup>24</sup> definition, we defined a "case" as a breast cancer survivor who developed lymphedema and who returned to employment or self-employment, following breast cancer treatment. The multiple cases are analogous to multiple experiments where "replication" logic is adopted; each individual case is a "whole study," which concludes the phenomenon independently and was tested by replication with other (multiple) cases.<sup>24</sup> By comparing and contrasting cases, we identified the factors that predict work-return experiences. Yin's<sup>24</sup> approach suggests the focus on research questions throughout the data

collection and analysis with the guidance of prior-developed theoretical propositions.

### *Participants and setting*

Breast cancer survivors were eligible to participate if they: (1) were more than 12 months post-surgery and radiation treatment; (2) were subsequently diagnosed with lymphedema; and (3) were employed or self-employed at the time of developing lymphedema. Persons who were unable to articulate their experience and thoughts in English were not included in this study. Purposeful sampling was used for case selection, in which we recruited the collective cases that were likely to have the most available data, maximum variation, and represent diverse perspectives. Potential participants were recruited from our institutional review board (IRB)-approved database of known survivors, as well as local hospitals, community health centers, breast cancer support groups, and survivors' events in a medium-size, Midwestern city. Flyers for patients and health providers, as well as facility staff, were disseminated in approved hospitals, community health centers, breast cancer survivor group events, and via emails to known survivors. Interested individuals were informed about the details of the study and enrolled with written informed consent. Data collection occurred in a private clinic or conference room setting. Participants who were unable to travel for the interview were given the option of interviewing over Skype,<sup>25</sup> a video-conferencing tool. A total of 13 breast cancer survivors were interested in participating and recruited in this study.

### *Data collection*

Data were collected between June and November 2017. A structured, investigator-developed data collection tool was administered to each participant, followed by a 60-min, one-on-one semi-structured interview. Follow-up interviews were conducted to validate and enrich specific ideas when the information in the initial one was not clear. The data collection tools were developed based on researchers' expertise, literature review<sup>6</sup>, and findings of previous studies.<sup>26</sup> The researchers had extensive experience in breast cancer survivorship and lymphedema research, cancer rehabilitation study, and qualitative methodology approaches. The pre-interview data collection tool asked questions about demographic information (e.g. age, marital status, education level, adequacy of financial resources), clinical characteristics (e.g. breast cancer treatment, lymphedema diagnosis, co-morbidities), and employment information (e.g. occupation, working hours, time off, insurance). The semi-structured interview guide developed based on the research questions and concepts of ICF included questions regarding: (1) work content, demands, and meaning to individual; (2) lymphedema-related changes, including physical, emotional and interpersonal changes; (3) work-related outcomes, including engagement

in work, job continuance, ability to do work tasks, performance, and workplace relationships; (4) work environment, including work-related social support; (5) reflections on personal experiences; and (6) having lymphedema after breast cancer treatment, in general. All interviews were administered by one researcher and audio-recorded using a digital recorder for in-person interviews and Ecamm Call Recorder for the Skype software<sup>27</sup> interview. A journal entry was written after each interview to summarize and highlight details that might be informative for follow-up interviews and data analysis (e.g. notes of any confusions and possible bias) and to document any unusual (e.g. less neutral feelings and possible role conflicts) or otherwise interesting observations during the data collection process.

### *Data management and analysis*

Data were stored securely, and access to the data was limited to the researchers and trained personnel associated with this study. Data obtained were recorded through a code system in which each participant's name will be linked to a number so that each participant cannot be identified directly from the data. Audio-taped interviews were transcribed verbatim by research associates and double-checked. Any identifying information that was provided by the participant in the course of the interview (i.e. names of persons and companies) was removed after transcription. The transcripts then were imported into the computer-based software program Dedoose<sup>28</sup> for analysis. Transcripts were subsequently read through for overall impression and initial coding-tagging. The portion of each transcript linked to the codes was labeled and noted. A within-case analysis was conducted for each participant using *constant-comparative method* including identifying and categorizing instances with similar properties from the data; comparing the properties with each set of categories; and generating themes related to the research questions.<sup>29,30</sup> Next, the themes/findings across the different participants were compared, and the categories of the data that were identified across the cases were redefined and drawn into themes for the multiple cases. The data collection and analysis were carried out simultaneously until data saturation was reached. Coding and themes emerged were agreed upon all three authors. Data from all 13 participants were included in the data analysis. A peer-debriefing session was employed, in which five methods experts and experienced researchers in this field were invited to review the study design, procedures, and analysis strategy. Moreover, participants were followed up for feedback on the findings to identify biases.

## **Findings**

### *Case context*

Full informed consents were obtained from 13 survivors. Participants were predominately from a Midwest state, and

**Table 1.** Context of cases.

Context of cases	Description (N = 13)
<b>Demographic characteristics</b>	
Age	40–77 (median 62), <65 years (77%, 10/13)
Ethnicity	White (11), Black (2)
Education	≥college (10/13)
Living with family	With a partner (6), With children (4), Alone (3)
Marital status	Married (5), Divorced (6), In relationship (1), Single (1)
Financial status for household	Extremely adequate (8/13), Somewhat adequate (5/13)
Level of social support	High degree (7/13); Above average (6/13)
<b>Disease-related characteristics</b>	
Time since surgery and radiation	6 months–27 years (median: 5.25 years)
Breast cancer survival time	8 months–27 years (median: 5.3 years)
Time with LE	1 month–24.5 years (median: 2.8 years)
LE on the dominant side	9/13
Who initially detected the LE	Detected by themselves and they sought medical diagnosis (10) By following up with their oncologist (1) By following up with primary care provider (1) Participation in a breast cancer study (1)
Cancer treatment types	Surgery (100%, 13): lymph node removal (10/13), mastectomy (9/13), lumpectomy (10/13) Radiation (7/13) Chemotherapy (10/13)
Symptoms of LE	Heaviness (n = 10), upper extremity weakness (n = 6), aching (n = 7), and sensation alteration (n = 9; e.g. numbness, firmness, stiffness)
Change of health well-being	After LE: Good to moderate (n = 2), mild (n = 2) impairment After BC: good health all the time (n = 5), impaired mildly (n = 4)
<b>Employment characteristics</b>	
Occupational type	Professional/White-collar (9), Blue-collar (3), Other (1)
Change of occupation	Stay the same (12); Change to other (1)
Change of working hours after LE	Significant reduction of work hours (2)
Restriction to work duties	Restriction to some duty and need workplace modification (6), No restriction (6)
Size of business <sup>a</sup>	Medium (6), Small (5), Large (2)
Insurance	Employer insurance (10); Private insurance/own paid LE cost (3)

LE: lymphedema; BC: breast cancer; RTW: return to work.

<sup>a</sup>Medium = 100–499, Small = 1–19, Large ≥ 1000.

the surrounding area, and enrolled through diverse recruitment approaches, such as breast cancer survivorship events, support groups, referral by health providers and enrolled participants. All interviews were conducted in person, except one distant interview was conducted via Skype. Demographic, disease-related, and employment-based information were collected (Table 1).

**Demographic characteristics.** Most participants lived in or near small metropolitan areas in the Midwest. The majority of the participants were employed at the time of the interview, and the majority of the participants were Caucasian. Education level and financial status tended to be reported as high. Social support also was self-reportedly high among the group (Table 1).

**Disease-related characteristics.** All participants had undergone breast cancer surgery. Time-since-surgery ranged from 6.5 months to 27 years prior to enrollment in the study.

(The 6-month post-surgery participant is an IRB-approved alternative case.) The majority had lymph node removal and mastectomy, lumpectomy, or both. More than half of them also had radiation and chemotherapy. The initial diagnosis of lymphedema ranged from 1 month to 24.5 years prior to the interview. The majority developed lymphedema on the side of their dominant limb, and symptoms including heaviness, upper extremity weakness, aching, and sensation alteration were reported most frequently. Most women recalled detecting lymphedema by themselves, and they subsequently sought the medical diagnosis. About one-third of participants reported having depression, and an equal number reported a change of health and well-being after developing lymphedema (Table 1).

**Employment characteristics.** The participants' occupations in our sample included both sedentary jobs, such as office work, and more physically demanding jobs, such as natural sciences fieldwork and stocking items in the store. The

majority of the participants continued in their previous occupations after lymphedema diagnosis, except a food demonstrator who worked as cleaning staff before her lymphedema diagnosis. More than half reported no formal restrictions regarding their work arrangements. In contrast, four women were restricted to light-duty and two needed some workplace modification or modified work hours. Most participants did not take time off from work or took off only a few days in total for lymphedema treatment. The exception was an individual who took 5 months off from work from her cleaning duties after lymphedema diagnosis. All participants commuted to work within 20 min driving distance. A large majority had an employee-based health insurance, with full or deductible-only coverage for lymphedema treatment (Table 2).

### Main themes

Four main themes emerged from our interviews: (1) BCRL affects physical and emotional functioning associated with work; (2) ongoing treatment for BCRL creates challenges for work; (3) environmental factors affect the return-to-work experience; and (4) personal factors play a key role in adjusting to return-to-work.

*BCRL affects physical and emotional functioning associated with work.* Participants in this study reported both physical changes and emotional distress caused by lymphedema. The physical, emotional, and interpersonal factors reported by our sample seemed to highly interact with one another and collectively influence an individual's return-to-work experience. For example, the wildlife scientist (05) had experienced significant physical dysfunction because of BCRL-related infections, which in turn caused chronic fear of potential future infection and related repercussions. Her fear made her increasingly cautious, preventing her from being spontaneous and fully functioning. Also, her negative body image caused her to be self-conscious and thus altered interpersonal function. Another participant, the private business owner (10), experienced emotional distress due to her decreased work productivity. Her distress also was fueled by questions of body image. Ultimately, she became more socially reserved. For a long-term view, physical function impairment would potentially be lessened by rehabilitation and adaptation, while emotional and interpersonal distress might be more predominant, depending on the availability and adequacy of the individual's resources and might benefit from counseling.

*BCRL affects physical functioning.* Decreased physical function was especially likely when there were complications from an infection. The most frequently identified limitations included upper extremity strength and range of motion, endurance for carrying, bending, and decreased fine motor skills, such as would be required to

pick up a pen (Cases 06, 08, 09, 12, 13). These concerns, which arose in the context of the interview, are consistent with survey data, including the report of upper extremity weakness, limited upper body movement, and upper extremity symptoms including altered sensation, heaviness, and aching.

*BCRL causes long-term emotional distress.* The participants also reported long-term emotional stress and many participants considered this to be a greater problem than physical limitations in the long-term. As the customer service representative (07) said, "*It's been 8 years . . . it probably affects you more mentally, than physically.*" The primary source of emotional stress included fear of BCRL-induced infection, which was especially pressing for participants who had experienced infection before. Participants who had experienced infection perceived a need to act more cautiously to avoid infection risks which, in turn, created a barrier to being able to act spontaneously at work. Selected quotations are provided below that demonstrate their fears related to infection-related concerns.

That cellulitis experience really laid me up and financially it's very expensive . . . It's hard not to just be able to be spontaneous and like, do things; that's the hardest part, is not being spontaneous, so I don't know how to not make it a drag . . . like a lot of my work that I've done in the past is, I'm outside and I'm in the elements; I'm digging in the dirt and getting scratched up and stuff. So to me, I feel like I need to be in a plastic bubble. (Wildlife scientist 05)

I've had two infections in the last year in my arm, where my arm, got hot and beet red and I had to go to Urgent Care. So you do have to be more careful with it, and that was part of it, too, you know just having to watch: Am I gonna get a stick from one of my flowers or a thorn or something? (Customer service representative 07)

I think in the back (of my) mind, I worry that I'm gonna get a cut on my hand. Or some, something is gonna happen and it's going to get worse and then it's gonna get bigger and then it's never gonna . . . I get a little nervous because I'm worried something is going to happen to my arm. (Fitness instructor 08)

Another major source of stress is that participants wanted to be perceived by co-workers as being just as capable and dependable as they were prior to BCRL. However, because of their physical limitations, they perceived themselves as less productive than they were prior to BCRL. In addition, they felt they were perceived as less dependable by their workplace peers, which was very frustrating and added to their sense of lost control. Frustrations related to their work performance caused by BCRL are depicted in selected quotes below.

**Table 2.** Case employment characteristics.

Case ID	Occupation	Employment status	Hours per week working; change since breast cancer and since LE	Time off between BC and RTW	Time off due to LE	Time to commute to work	Health insurance
01	Insurance claim representative	Working full-time, no restrictions	45 h no change	4 weeks	Couple hours per week $\times$ 4 weeks	Drive 20 min	Employer-based
02	(Grocery store) Food demonstrator	Working, but restricted to light duty; working at lower wage; fewer hours than before LE	84 h before BC 0 h after BC 6–24/week after LE 40 h, no change	9 months	5 months	Drive 20 min	Self-paid insurance
03	Clinical lab technologist	Working full-time, no restrictions	40 h, no change	4 weeks	2 days	Drive 5 min	Employer-based
04	Medical technician	Working full-time, no restriction with assistance	40 h, no change	1 day	0	Drive 10 min	Employer-based medicare
05	Wildlife scientist	Working full-time, restricted to light duty	60 h before BC 15 h after BC 40 h after LE	Part-time 15–20 h	3 days due to infection	Walk 30 min	Student insurance
06	Nurse	Working full-time, no restrictions or modifications	40 h, no change	2 months	5 days	Drive 30 min	Employer-based
07	Customer service representative (and hospital volunteer)	Working full-time, no restriction	40 h, no change	0	0	Drive 10 min	Employer-based full LE coverage
08	Fitness instructor	Working part-time, no restriction (retired from primary service job due to BC treatment)	40 h before BC 15 h after BC (no change after LE)	1 week	1 day	Drive 15 min	Retiree Insurance from former employer deductible \$3000
09	Home healthcare provider	Working part-time, restricted to light duty	60 h before BC 22 h after BC and LE	2 years	0	Drive 7 min	Medicare Parts A and B 80% physical therapy Self-paid garments Self-paid insurance No LE coverage
10	Private business owner	Working full-time with modification	65 h before BC 60 h after BC 50 h after LE	2 weeks	0	0 min (home office)	Self-paid insurance No LE coverage
11	(Middle) school teacher	Working full-time, no restriction	36 h no change, full summer break	2.5 weeks	1 day/month	Drive 20 min	Employer-based Deductible
12	Grocery store staff	Working full-time, restricted to light duty	40 h, no change	10 days	0	Walk 5 min Drive 1 min	Through employer deductible with 100% coverage
13	Insurance underwriter	Working full-time with modification	60 h before BC 40 h, no change before/after LE	8 weeks	0	Drive 10–15 min	Through employer Deductible with 100% coverage LE

LE: lymphedema; BC: breast cancer; RTW: return to work.

I'm pretty fast at my job and I'm one of the quickest underwriters. So to be in a situation where I can't function, based on something I can't control, is very frustrating. (Insurance underwriter 13)

I was always depended on to be there. If one of them, if somebody woke up sick and they knew I wasn't working or that I was working one of the other shifts, they would call me and switch shifts or something, and now it's like they're afraid to. It feels like my life has changed to where I have no control . . . Being depended on. I like that they can depend on me. (Grocery store staff 12)

As the participants note, the sense of lost control and emotional distress seemed to be driven by a tendency to compare their current abilities to their previous level of function and by the discouragement of being viewed by co-workers as less competent. In general, there was an overarching desire for life to be the same as before BCRL. Yet, the realities of BCRL created barriers to normality.

**Ongoing treatment for BCRL creates challenges for work.** Returning to work while continuing treatments for BCRL increased the challenge. Survivors complained that bandages, compression garments, and sleeves could be more bothersome than BCRL itself and that the bandages could limit physical function and interfere with work activity more than BCRL alone. The garments and bandages were uncomfortable and distracted participants from their job. Less directly, using bandaging and garments added a time burden to participants' daily routine and affected their after-work social life.

**Bandages compromise work activity.** Participants reported that upper extremity function was affected dramatically during the time of acute therapy, at which point most participants used some sort of compression bandaging. Multi-layer bandaging was the most cumbersome from the participants' perspective and was inconvenient for both office workers and workers with more physical jobs. The heaviness and bulkiness of the bandaging impeded upper body movements, such as raising the arm and keeping it raised, bending the arm, and fine motor movements. Work skills such as typing accuracy, writing in longhand, pushing objects (e.g. the cart at the grocery store), and picking up small objects were dramatically affected.

In addition to being cumbersome for work tasks, participants also complained about discomfort (e.g. hot and restricting circulation) caused by garments that related to disturbance and reduced productivity at daily work. The warmth was the most bothersome feature, and discomfort increased the longer the garment was worn (Cases 06, 07, 11). The nurse (06) discussed traveling for business by car, in the summer: "*The sleeve, they get really hot . . . It binds me and, in the summer, it's worse because it's sweaty.*" Hot flashes, which may be experienced as a sequela of cancer treatment, compounded the problem. The home healthcare

provider (09) said, "*It's just too hot . . . Since the surgery, I've had really bad hot flashes. So, with the hot flashes, it's hard for me to wear the bandages and the sleeve.*" Given that BCRL is a chronic and lifelong treatment effect, discomfort from the side effects of treatment is also likely to be prolonged and, therefore, discouraging. Circulation problems (Cases 01, 05, 06, 13) were reported as a result of poorly fitted garments or wearing the garment inappropriately. But problems with fit were not always easily remedied. For example, the wildlife scientist (05) said, "*Sometimes feeling like my arm circulation is getting cut off because of the sleeve, because of the angle of how my arm is . . . My sleeve wasn't on right.*" The insurance claim representative (01) said, "*(The sleeves) . . . hurt and makes the hands swell more.*"

Bandage and garments also indirectly interfere with work activities. Many examples of interference were shared. For example, the fitness instructor (08) said: "*I was teaching an aqua class for arthritis sufferers. And, so I couldn't get in the water; obviously. So I had to teach the class, you know, from the outside of the pool.*" Another participant, who traveled for business purposes (Nurse 06), described being pulled out for a body search when she went through security at the airport with her bandaging. Also, for some work activities, it was necessary to maintain cleanliness, such as by wearing gloves, but this made some jobs more difficult. Examples included the clinical lab technologist (03), whose job required wearing laboratory gloves every day. A participant whose job required high levels of hand hygiene found frequent hand washing difficult with hand bandages or compression gloves. The food demonstrator (02) mentioned, "*It's hard to keep the glove (hand compression gloves) clean all day.*" Also, participants described difficulty maintaining the bandages' good fit throughout the day. Making adjustments was described as inconvenient at work. For example, the grocery store staff (12) said, "*I've had to tighten it up three or four times at work. Now when I put it on, I start snug and when it starts getting loose, I tighten it up more and more and more.*"

It is worth noting that even though there were many complaints, many participants still admitted that the bandaging treatment alleviated the symptoms of BCRL and prevented exacerbation. Therefore, in some ways, the bandages had a positive effect on their functioning at work.

My skin itches because it's so swollen and it hurts because it's so swollen, but as long as I have these on it kind of keeps the swelling down and so it doesn't hurt, and I can get more done, it just makes my arm feel heavier. (Grocery store staff 12)

I wish I didn't have to wear all of that because I feel just—smothered, most of the time, but when I'm lifting, I feel so much better that I can have the bandages on because they do help me. I don't have to worry about if I'm going to pick up too much fluid . . . I don't have to worry about if maybe

the arm is going to get swollen. It can't because I have the bandage which protects the arm. (Home healthcare provider 09)

*Bandages draw unwanted attention and distract from job role.* More generally, participants were frustrated at being the objects of attention in public including work settings because of their obvious bandages and compression sleeves. They disliked having to repeatedly explain about lymphedema and why they wore these garments at the workplace and the general public. The problem is compounded because it is a difficult thing to explain.

I'm embarrassed when I have to wear it because someone's always asking me what's going on. I repeat it. I'm not fine with it because it is irritating at once. People keep repeating the same thing. When I go anywhere, they ask me why I have the sleeve. (Home healthcare provider 09)

It draws attention to it. I don't wanna tell the story over . . . I have no problem telling people, but when it's, like, so much attention to it and you're, like, I've told this story, like, 100 times. (Wildlife scientist 05)

When I'm telling them about it, sometimes I feel frustrated because I can't tell them this is what's gonna happen; this is a way my life could be forever or it's gonna go away . . . And when I don't wear it, they may have a comment that you should handle (it), your arm is so swollen. So people even notice it, when I don't wear them. (Insurance claim representative 01)

For many participants, wearing bandages and sleeves caused a constant state of self-consciousness at work, which led to uncomfortable feelings in public and when interacting with people.

You know having to wear that big wrapped arm, I was self-conscious about that, and even when I had to wear my garment, I was at the beginning very self-conscious. (Clinical lab technologist 03)

The nurse (06) reported the bandages drew attention from the audience while she was giving presentations for work. This problem was shared by others, such as the school teacher (11): *"I noticed sometimes when I point at the board or something, sometimes kids like, you know, it's distracting to them."*

*BCRL management affect work lifestyle.* Some aspects of lymphedema management created areas of frustration that were less directly related to work skills and productivity, but meaningful in the overall scheme of one's daily lifestyle while working. Examples started with the beginning of the workday, as donning the lymphedema bandages can be time-consuming and the bandages themselves can impede the morning routine as much as they impede work activities. For example, applying makeup and brushing/

styling hair required raising the arm for long periods of time, which was difficult. These things increased the time burden for already-busy career women.

It means that you have to get up earlier because it takes me about half an hour to wrap, to get it all wrapped, and get cleaned up. So you'd get up and you shower, and then I'd have to sit down figure out how to get my wrap on which is complicated. (Nurse 06)

The women spoke about how the stress of wearing lymphedema treatment appliances had a negative effect on their after-work social life with their colleagues. The reasons they gave included unwanted attention and altered self-image, as well as discomfort and inconvenience.

It prevents me from doing anything, because, first off, I don't want the attention and, second, it's cumbersome, so (I) don't want to be hot. I don't want to sweat in it. I don't want it to get wet. I don't want to be in the rain. I don't want anything . . . I would've just went home, um, after I get off work. I got home and I just wrap it, and so it's very rare I will make plans after work right now. (Insurance underwriter 13)

Women felt that the bandages/sleeves were unsightly. The compression garments did not look appealing and might not match their outfit. They might portray a "sick" image in public. For example, the fitness instructor (08) said, *"I didn't really wanna go out with all that wrapping either that much . . . Well, just because it looked silly."*

*Environmental factors affect the return-to-work experience with BCRL.* Participants in this study discussed a number of environmental factors negatively affecting their experience of returning to work. These included not only the work environment *per se*, but also a general lack of knowledge about lymphedema. On the positive side, a wide range of environmental supports was perceived, including informational and educational support, functional and practical supports in the workplace, and social support from various sources.

*Limited BCRL awareness and resources for patients pose barriers to work-return.* Almost all of the women talked about the lack of BCRL awareness by the public, which included their workplaces. Participants said that the general public largely did not know what BCRL is. Lack of knowledge among the general public made the survivors with BCRL feel conspicuous and misunderstood.

I think that the general society . . . because people, they don't think that, like, lymphedema is that big of a deal or that much of an issue . . . I think the lack of understanding that people who go through cancer treatments . . . especially, if they have new medical conditions because of their treatments. . . (Private business owner 10)

Participants expressed that this general lack of knowledge of BCRL resulted in the misunderstanding between them and their colleagues at times.

In some ways it's hard because you look normal, but then people want you to do things like help them move furniture or help them dig a ditch. I have to be cautious about this, and they look at you, like, "What are you, crazy?" . . . so it's, like, until you really physically look ill, people don't really understand it. (Wildlife scientist 05)

Participants felt it was hard to gain support if the people around them did not understand their situation and what they had been through.

People think that once you heal from your cancer treatments and your hair grows back, and all of that, they think that you are back to the old person you were before all this, and not understanding that all of that treatment and going through, all of that really changes a person and that a lot of the times they have long-term new health issues that interfere with their quality of life or their ability to function. (Private business owner 10)

All participants reported receiving insufficient information and resources about BCRL, in general, let alone how this might affect work-life. Quite a few participants shared their difficult journey in searching for information about lymphedema and seeking diagnosis and treatment. This interview finding was consistent with the survey data that more than half of the individuals initially detected lymphedema themselves. Some women expressed unmet needs for individualized support from the healthcare providers regarding work-return advice. They mentioned that lymphedema education at the clinic might still be too generalized and structured, and the information about occupational rehabilitation related to lymphedema was barely provided.

When I talk to the doctor or somebody, I don't think they quite understand the nature of a lot of the work I've done . . . like I can do more stuff indoors now . . . like I can do a lot of computer programming and that kind of stuff, but I still wanna be able to go outside and be really physical with the earth. (Wildlife scientist 05)

It's too structured, what the information that is out there, and the information of how therapists, what they say to their people. If they fit into that box, you're all set, but if you don't fit into that box, you're kinda left there out all on yourself. (Private business owner 10)

*Social supports vary positively with work-return experience with BCRL.* Not all experiences were negative, however. Some participants shared about times that a clinician, family member, friend, or neighbor helped them with their difficulties. These supports were highly valued when

they returned to work. Medical support and education from healthcare providers made it easier for participants to follow their treatment plan. In the acute treatment of BCRL-induced infection, when antibiotics were needed immediately, supportive clinicians made a positive impact (Nurse 06), answering occasional questions (Customer service representative 07). Some clinicians provided compassionate listening when a participant just wanted to tell a health professional about their difficulties (Medical technician 04). Participants expressed that those supports from the clinicians made their lymphedema management easier while going back to work.

Others in the home environment had a largely positive impact on participants, as well. Married women often reported that their partners were helpful with bandages (Cases 03, 09, 08). In contrast, women living alone might not experience this support. For example, the private business owner (10) was single and experienced challenges in living with BCRL and working to support her family. Single women sometimes had support from their friends or parents (Insurance underwriter 13) who helped them get through the difficulties. Support from neighbors and communities also were mentioned as having a positive effect when participants returned to work (Cases 09, 12). Positive reinforcement from the people around them could be an emotional support to motivate and encourage those with BCRL. The fitness instructor (08) noted: "*This morning one of the ladies in my fitness class . . . she told me, 'I can't believe how strong you are,' so I always get positive reinforcement from people.*"

Participants provided examples of how people in the workplace provided practical and emotional support. The school teacher (11) noted: "*I have a lot of friends that are teachers that would've, if I needed to leave, would cover my class and help me out.*" But not all survivors felt supported and some even felt threats to their job. As an example, the grocery store staff (12) noted experiencing conflicting information from higher-ups.

The store manager, he's always telling me to make sure and take care of myself. He tells me to put myself first, not to worry about it, not to worry about my position—it will be there. The other assistant managers, they're always helpful. They'll come up and be like, 'You're looking tired. You need to take an extra break,' or, "Do you need to take an extra break?" (Grocery store staff 12)

In contrast, she also recalled: "the HR person that had me in tears several times and kept telling me there was a chance that I was going to be terminated before all of this was over." (Grocery store staff 12)

In the workplace, participants said that having a flexible work schedule and sick leave was very helpful for lymphedema treatment, especially during the acute phase. It allowed them to go to medical appointments and also to manage lymphedema on a daily basis. Some participants,

such as the customer service representative (07), had sufficient employer-based sick leave. The private business owner (10) could set her own schedule. The insurance claim representative (01) worked out an arrangement with her employers: “They would allow me that time off, but paid. They allowed me the flexibility to work, [to] just make it up.”

Participants described impacts related to their health-care insurance coverage which is one of the workplace financial supports for lymphedema management. Those who worked at the big company seemed more satisfied with their coverage: “I just had to pay a co-pay to go to the lymphedema clinic. But they covered 100% on the sleeves.” (Customer service representative 07). But not all participants had generous benefit plans. For example, the food demonstrator (02) shared that her insurance company only allowed her one lymphedema visit. Women expressed sufficient health insurance contributed to their adherence to lymphedema treatment while returning to work.

*Personal factors play a key role in adjusting to return-to-work.* A number of personal factors came up that were identified as helping participants as they returned to work. Broadly, these included personal motivation, having a level of comfort with seeking help, and having a positive attitude when facing challenges. Participants frequently identified areas of personal growth that occurred because of the adjustment process.

*Motivation to work drives the work-return.* Motivation was identified as an important individual determinant for returning-to-work, even though the specific reasons for feeling motivated differed from individual to individual. Several women felt motivated by their enjoyment of their work and/or the sense of accomplishment that work provided (Case 01, 03, 04, 13). The insurance underwriter (13) conveyed this well by saying,

I like working. It's a place I can do something. When I do my job, part of what we do is safety-related, so I feel like I'm giving back to the community. Even when I had cancer, it was a place that kept my routine going. So I really enjoyed coming to work, doing something productive. (Insurance underwriter 13)

She also appreciated the structure of work and the fact that it helped her to stay in a normalizing routine: “It's a part of what I do, like, I couldn't imagine not working. So it's very (much) a part of my day.” This perspective was shared by others, especially participants who lived alone (i.e. Insurance claim representative 01).

Financial security also was identified as an important source of motivation. The food demonstrator (02) said: “I've been independent . . . I've always worked, I've always taken care of myself, so I don't wanna stay home and sit and do nothing.” Along similar lines, the insurance underwriter (13) commented: “I gotta work around it

[effects of lymphedema], you know, and I don't think anyone else is responsible for my life but me.” Although for many participants, the financial need was a very concrete reality. “It's paying doctor bills and other bills so that we can live in a house and have a car.” (Grocery store staff 12) For at least one participant, the financial benefits of work allowed her to splurge: “I love money. And although I and my husband have a pretty good income coming in, I always want to make more money because I love to just buy things.” (Home healthcare provider 09)

*Comfort in seeking help eases the difficulties.* Women in the study shared their need to ask for help. Although they seemed to think this was a good thing to do in the abstract, most indicated that they found it uncomfortable and disliked having to do it. This personal attribute could make a difference in overcoming difficulties at some points as asking help is one of the coping strategies. The wildlife scientist (05) was among those who had to learn to ask others for help:

I think one of the biggest things I've learned is that I have to ask for help and I can't do everything on my own and that was a very big challenge for me because, as I said, I was very independent. (Wildlife scientist 05)

Some women didn't ask for help because they perceived that others were burdened by these requests. For example, the private business owner (10) said: “I don't really ask for help, but people also don't offer to help . . . Figure it out on your own, so you can stay connected to people.” The private business owner (10) went so far as to express concern that she might be judged negatively: “They just feel like breast cancer survivors who say they now have lymphedema are basically just wanting attention.” In contrast, the medical technician (04) was comfortable seeking help and support and encouraged others to do so. She said,

I get help. You know, get someone to come and help you . . . and just . . . you know your limitations. You know that you're not gonna hurt yourself because it was . . . I mean; I knew my handicap. It's like a person who had a handicap knew how far they could go. (Medical technician 04)

*Positive attitudes toward challenges are essential in coping.* A number of individuals seemed to be able to maintain a positive outlook when difficulties arose and these positive attitudes helped them to cope with BCRL. The fitness instructor (08) was one such individual: “I think, just growing up, I was taught that you can either complain about your life situations or you can accept them, and find something positive out of whatever life throws your way.” A positive attitude was presented in different forms. For example, the home healthcare provider (09) used a self-affirming approach:

I just feel blessed because not a lot of people get along good like I do . . . I've come this far and done what I've done. So I feel very good about myself . . . and if I have to deal with lymphedema, that's just a little, small thing I'm going to have to deal with. (Home healthcare provider 09)

The fitness instructor (08) seemed to even experience a measure of pride in overcoming lymphedema: *"I think people that know me and know that I wear this and the reasons why I wear it are proud of me."*

An important resource for maintaining a positive frame of mind revolved around their spiritual habits and beliefs. The grocery store staff (12) shared her perspective about God's role in her healing process: *"I believe there is a God and I believe that He cares about us and that He's there for us when we need Him. I prayed a lot more during this, for strength to get through it."* The home healthcare provider (09) also used spiritual language when talking about her mental strengths:

I felt so fortunate. I felt blessed. I'm a very godly person, so I felt that I had all of this because of God. I don't leave Him out of the equation. He's always with me. The way I feel, you can do all things through Jesus Christ which strengthens you. (Home healthcare provider 09)

A final form of positive coping was the ability to put things into perspective. For example, the home healthcare provider (09) emphasized that she was able to do everything she did before, just with a greater level of discomfort. Some participants noted that BCRL was uncomfortable, but when compared to other events in their lives, it was manageable. This was the case for the medical technician (04) who observed: *"It's not a disability to me yet. More disability was my heart to me."*

*Coping strategies were developed along the way to work-return.* The participants in this study described a range of work-related coping strategies and mechanisms. For the most part, these were not innate, but rather learned through experience or developed in the face of necessity. Two facets of coping were time management and the development of adaptations to address their changing functional status.

As mentioned above, BCRL management added a time burden to the individual's daily routine and the women we interviewed described having to make space for BCRL management on their daily to-do list. Some examples included the insurance underwriter (13) who skipped lunch when she needed to do a self-management task, and the insurance claim representative (01) who tried to make her therapy appointments around her work schedule, in the morning or late afternoon. The fitness instructor (08) worked around a complicated schedule to apply her wrap, but also maximize her teaching:

I might go teach my class at eight using the sleeve, then come home and have him (spouse) help me wrap my arm well, for the

rest of the day. For those classes, I just wore the sleeve. But then when I went to do my aqua class, I wrapped it. I would just do my instruction on the outside of the pool. (Fitness instructor 08)

The wildlife scientist (05) took a different perspective, prioritizing self-care over work:

(When I) have these appointments I have to go to, I just penciled it in . . . and (it has to) just be like, this is part of my job right now is, taking care of my health and because I treated it that way, it was so much easier to deal with that. It was just something that needed to be done. (Wildlife scientist 05)

Women were faced with myriad functional challenges in the course of chronic BCRL and addressed these practically and creatively. For example, the nurse (06) had difficulty with lifting and typing,

I also started using roller bags, so I didn't have to carry as much, so that was an adaptation I made . . . I got something to put my arm on, so that I could hit the keyboard a little bit. So I got some tables and elevated my arm, so I could reach the keyboard a little better. (Nurse 06)

They also reported being creative to cope with the unpleasant image of lymphedema garments in the workplace. One participant (Customer service representative 07) reported: *"I got away from the brown (color) that looks medical. I've got some that are kind of fun colors. The gray, to me, doesn't look as medical as the, you know, everyone that has the beige."*

To avoid work-related hazards that might have a negative impact on BCRL, such as heavy-duty tasks or infection exposure, some women adjusted their work activities, while others decided to change jobs altogether. For example, the grocery store food demonstrator (17) had quit her physically-demanding job as a house cleaner. The home healthcare provider (09) stopped accepting clients with mobility disorders who required assistance with transfers and switched instead to light-duty work, such as giving medications. Lymphedema inspired some women to incorporate BCRL advocacy in their work, to help others and increase awareness. The clinical lab technologist (03) started a local support group. The private business owner (10) changed her business from interior design to lymphedema compression garments and kept up with the newest innovations. The customer service representative (07) has taken her knowledge of BCRL and now focuses on providing education to patients and families in the clinic as a volunteer.

## Discussion

Our findings indicated that BCRL negatively influenced women's physical, emotional, and interpersonal functions and that this, in turn, had an impact on their work lives.

Our findings are consistent with the majority of the literature, which has shown less satisfactory physical and emotional well-being among breast cancer survivors who developed lymphedema, compared with those who were lymphedema-free.<sup>31–35</sup> Moreover, we identified underlying reasons for the negative effects of lymphedema on survivors' daily life, including in their work environment.

Examples of physical challenges at work included decreased strength of upper extremity and chronic symptoms of lymphedema. Our study also notes that the swelling and pain associated with lymphedema can be challenging when engaged in typical work activities such as typing, lifting, and carrying. The progression of problems and symptoms worried our respondents with regard to their ability to continue doing their job adequately.<sup>36</sup> The manifestation of physical impairment seemed similar across cases. In contrast, the manifestation of the emotional and interpersonal disturbances seemed more diverse. We feel the diversity of the latter contributed significantly to the individualized experience of our respondents. It should be noted that the emotional distress our participants reported was intertwined with their physical changes. For example, women who felt they decreased in their physical capacity for work led to dissatisfaction with one's own work productivity. Participants shared that arm swelling and infections caused negative body image and self-consciousness at work and in work-related social life. Other studies have documented similar findings; that poor self-perception can remind survivors about their cancer and affect their interactions in work and social environments.<sup>37,38</sup> Female cancer survivors have been shown to develop anxiety and be vulnerable to negative social and interpersonal relationship changes.<sup>39</sup>

What has not been previously expanded upon are the functional challenges caused by the treatment of lymphedema. Based on our findings, the unacceptability and direct interference of bandaging treatment lead to physical and emotional distress at work, more than lymphedema alone. Moreover, the burden of daily lymphedema management (time-consuming, complex) also added stress to the individual's work-life routine and for some participants, created social anxiety. A recently published study re-conceptualized the "work" that women have to take on after diagnosis of cancer, such as the work of managing and attending various medical activities, the work of overcoming the physical and emotional challenges, the work of adapting to new lifestyle habits, the work of daily duties and paid jobs, and the work of prioritizing different types of work.<sup>40</sup> Our breast cancer survivors provided examples of all of these problems.

Our findings are consistent with the ICF framework with respect to an individual's functioning and how this was altered by BCRL and its treatment, and also the context in which they must function. The context included their work-related task demands and the environment (e.g. accommodations, supports) in which those demands are

addressed. For example, both the insurance underwriter and grocery store staff were in the acute phase of lymphedema treatment at the time of the interview. However, the insurance underwriter was doing light office work (e.g. typing and writing), while the grocery store staff performed tasks that were more physically demanding (e.g. pushing/pulling grocery carts and operating the cash register). As such, the latter found more restrictions and difficulties in work activities (e.g. she couldn't independently perform the tasks and required accommodation and assistance). In the case of the food demonstrator who worked as a cleaner before developing BCRL, she was no longer able to do what was required for her job. As there was no easy way to make accommodations, she had to give up the cleaner job completely. Despite many common experiences observed in our sample, individual's functioning, specific work activities, and their means for BCRL management differed from person to person. Thus, survivors' return-to-work experiences are highly individualized.

Although there was a considerable agreement between our findings and the concepts and propositions of the ICF model (i.e. functioning, work activity, contextual factors from the environment, and individual attributes are variables that shape work experience), our findings also raise questions for understanding the ICF model. Specifically, the concepts of "body function and structure" in the ICF are generally considered as physical changes. However, based on our findings, the emotional and interpersonal stressors caused by BCRL could be the most challenging aspects for some survivors. Depicting this becomes cumbersome in the ICF framework—in which consideration of emotional functioning is limited to partitioning it into a matter of diagnosis, personal factors, or environmental factors. For our participants, it is insufficient to merely describe them with a diagnosis of "depression" or "anxiety," or as having limitations of personal coping. Certainly, their experience cannot be boiled down to problems associated with unpleasant environmental factors, such as the curiosity of coworkers or the public. Another complex twist is that the impact of the disease on work-return experience may include the effects of the treatment, which could have both positive and negative influence.

Our participants reported more complex relationships between their experiences of BCRL and its impact on their work than is able to be represented by the ICF model. As noted by Hemmingsson and Jonsson<sup>41</sup> and we agree, the ICF model has important shortcomings in its ability to recognize the subjective experience of meaning and autonomy. The ICF also is limited in its ability to capture the dynamics of participation, especially when this may involve multiple situations. These authors argued that occupational rehabilitation should increase emphasis on client-perceived performance and clients' occupational choices, rather than objective measures by others.<sup>41</sup> Similarly, our findings highlighted the important role of the factors controlled by the individual in adjusting to return-to-work. A good example from our study

was the motivation for returning to work. Coping strategies and attitudes toward challenges seemed to play a key role in adjusting to the outcomes of work-return. The participants in this study all had returned to work and most had developed strategies to overcome or at least cope with the limitations and frustrations they perceived.

Novel to our study was the identification and exploration of BCRL-specific strategies—physical and emotional—that our participants used to facilitate their return-to-work. These were further individualized, depending on personal concerns, motivations and the resources available to each individual. Some strategies were very practical (e.g. discovering tools to aid functioning or adjusting work activities or roles to make the job more doable), others were more toward fortification of their internal states (e.g. joining support groups to exchange information or becoming advocates to help other people with BCRL). Although sometimes difficult and sometimes costly on a number of levels, these participants perceived their efforts as important and return-to-work as rewarding. Our findings provide evidence for a multidimensional view of environmental factors, as either facilitators or barriers for participation in return-to-work. For example, very protective colleagues may facilitate survivors' carrying out work and at the same time be a hindrance for them returning to normality (as well as introducing distress, as they may feel they are perceived vulnerable or incapable). Also, although some participants made time for lymphedema management during work breaks and after work, self-care often meant sacrificing an after-work social life.

Our work shines a spotlight on the continuing limited awareness of BCRL among the general public and among some clinicians, which our participants identified as one of the major factors affecting their adjustment. Studies have demonstrated the important role of occupational health nurses and supervisors at work in improving work experience.<sup>42-44</sup> Although breast cancer survivorship has become much more familiar to the public, having benefited from decades-long public education and awareness campaigns, this is not the case for BCRL. Because of the limited understanding of BCRL by employers, work colleagues, and clients, our participants frequently reported their abilities as being either overestimated or underestimated. This had an impact on their ability to obtain appropriate support and confronted survivors with a decision as to whether or not to more actively seek support.

Even with increasing public health awareness, lack of support (from workplace peers and supervisors, clinicians, or family) continues to be a potential barrier to returning to work for cancer survivors in general.<sup>45-49</sup> Support for returning to work among breast cancer survivors, as a specific sub-population, has not been well-studied. Given our results, and consistent with the more general cancer literature, at least some patients with BCRL seem highly motivated to overcome (or work around) such obstacles and return to the workforce.<sup>45,46,50,51</sup> Personality factors,

including positive attitude, as indicated by our findings and in other studies, are likely helpful,<sup>6</sup> but motivation and attitude may not be enough.

Hoving et al.<sup>52</sup> call for studies of interventions to include more attention, information, support, and advice on return-to-work issues in cancer survivorship, not only from healthcare professionals but also from employers—a recommendation that is consistent with the complexities of the ICF framework. Our findings suggest that important elements that interventions might address include: education about effective prevention measures for BCRL-related infections and the risk associated with BCRL to allow urgent antibiotic access; assessment and management of the functional impairment; examples of simple and low-cost job accommodations to consider (e.g. task changes, schedule changes, or adaptive equipment); evaluation of the negative effects of BCRL bandaging treatment on work functioning and potential adjustments; and education to increase the awareness of BCRL in the general public and clinicians. Other approaches might include preparing patients to respond to the interpersonal stressors associated with work, including how to discuss BCRL with peers and supervisors and how to effectively discuss needed work accommodations. Importantly, Short et al.<sup>53</sup> have shown that when work issues are addressed as part of the treatment, work-return after cancer treatment is more successful.

As such, the findings support the implication that both individualized patient-centered care and the availability of occupational rehabilitation services, even into the chronic phases of BCRL, would likely enhance the return-to-work outcomes. Given the challenges reported by our sample, it would be reasonable to suspect that some (and perhaps many) survivors need more pointed assistance to tap these resources effectively. The information provided by survivors in this study regarding barriers, contextual factors, and coping strategies provides a starting point for future studies aiming to develop evidence-based assessment and intervention strategies to maximize returning to work. The complexity of individualized care, which appears to be needed based on the multiple, interacting, and fluid factors that were observed, implies that an interdisciplinary approach may be the most beneficial approach to assessment and intervention.

Our sample perceived that negative attention, unwelcome curiosity, and misunderstandings about lymphedema were fairly common among clinicians, as well as the general public, which became one of the biggest barriers for survivors who were returning to work. The implication of this finding is that larger-scale efforts are needed to improve both education in the health professions and health literacy efforts aimed at the workforce (e.g. employers, managers, human resource providers). Moreover, BCRL and its treatment chronically impeded work and home life in frustrating ways. Innovative research is needed to improve BCRL treatment and innovative

development of less cumbersome and more attractive products to manage lymphedema also are needed.

Although our study provided novel and interesting findings, there are several factors that limit the interpretation and generalizability of the data. First, we purposefully recruited individuals who had returned to work to describe their perspectives and experiences. Our understanding of the phenomenon would be enhanced by obtaining interviews from survivors with BCRL who were unable to do so successfully. Perspectives from this angle would give us a better idea about which barriers are the most prohibitive and perhaps which coping strategies seem to be the most helpful. In addition, we only obtained interviews with survivors. Future work to integrate the perspectives of employers, human resource personnel, disability experts, and/or work peers may be helpful in providing realistic intervention solutions. Finally, a limitation of this study is the restricted geographic range from which we recruited participants. Future research could include participants from more urban and more rural areas, as well as areas with differing cultures, types of industry, and support resources.

## Conclusion

This study, which is among the first to closely explore the experience of returning-to-work after BCRL, moves the field of chronic cancer care forward by identifying areas where breast cancer survivors experience and overcome barriers, largely without empirically informed support from their healthcare professionals. Study participants perceived the experiences incurred from BCRL and its treatment as affecting the return-to-work process in a number of ways. Most concretely, they perceived effects manifested through impaired physical function, altering their work-life routine, and/or effects experienced on their psyche. Participants also described influences (both positive and negative) occurring outside of themselves, which could facilitate or impede the return-to-work experience. These factors were woven into complex combinations that created each individual picture. In summary, in closely exploring the experience of returning-to-work after BCRL, this study shines a spotlight on the gap between the end of traditional medical care and the establishment of a productive and rewarding “new normal” for breast cancer survivors.

## Declaration of conflicting interests

The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

## Ethical approval

All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional research committee and with the 1964 Helsinki Declaration and its later amendments or comparable ethical

standards. This has been approved by University of Missouri Health Sciences Institutional Review Board (IRB SBS# 2003958).

## Funding

The author(s) disclosed receipt of the following financial support for the research, authorship, and/or publication of this article: Toni and Jim Sullivan Endowed Research Fund from Sinclair School of Nursing at University of Missouri-Columbia, faculty research funds from College of Nursing at University of Missouri-Saint Louis.

## Informed consent

Informed consent was obtained from all individual participants included in the study.

## ORCID iD

Yuanlu Sun  <https://orcid.org/0000-0002-8277-1401>

## References

1. American Cancer Society. *Cancer facts & figures 2018*. Atlanta, GA: American Cancer Society, 2018.
2. Bluethmann SM, Mariotto AB and Rowland JH. Anticipating the “Silver Tsunami”: prevalence trajectories and comorbidity burden among older cancer survivors in the United States. *Cancer Epidemiol Biomarkers Prev* 2016; 25(7): 1029–1036.
3. Howlander N, Noone AM, Krapcho M, et al. *SEER cancer statistics review, 1975-2014*. Bethesda, MD: National Cancer Institute, 2016, [https://seer.cancer.gov/csr/1975\\_2014/](https://seer.cancer.gov/csr/1975_2014/)
4. Richardson A, Addington-Hall J, Amir Z, et al. Knowledge, ignorance and priorities for research in key areas of cancer survivorship: findings from a scoping review. *Br J Cancer* 2011; 105(Suppl. 1): S82–S94.
5. Feuerstein M, Todd BL, Moskowitz MC, et al. Work in cancer survivors: a model for practice and research. *J Cancer Surviv* 2010; 4(4): 415–437.
6. Sun Y, Shigaki CL and Armer JM. Return to work among breast cancer survivors: a literature review. *Support Care Cancer* 2017; 25(3): 709–718.
7. Nguyen TT, Hoskin TL, Habermann EB, et al. Breast cancer-related lymphedema risk is related to multidisciplinary treatment and not surgery alone: results from a large cohort study. *Ann Surg Oncol* 2017; 24: 2972–2980.
8. Warren LEG, Miller CL, Horick N, et al. The impact of radiation therapy on the risk of lymphedema after treatment for breast cancer: a prospective cohort study. *Int J Radiat Oncol Biol Phys* 2014; 88(3): 565–571.
9. Zou L, Liu F-H, Shen P-P, et al. The incidence and risk factors of related lymphedema for breast cancer survivors post-operation: a 2-year follow-up prospective cohort study. *Breast Cancer* 2018; 25(3): 309–314.
10. Bernas MJ, Askew RL, Armer JM, et al. Lymphedema: how do we diagnose and reduce the risk of this dreaded complication of breast cancer treatment? *Curr Breast Cancer Rep* 2010; 2: 53–58.

11. Brennan MJ and Weitz J. Lymphedema 30 years after radical mastectomy. *Am J Phys Med Rehabil* 1992; 71(1): 12–14.
12. Armer JM and Stewart BR. Post-breast cancer lymphedema: incidence increases from 12 to 30 to 60 months. *Lymphology* 2010; 43(3): 118–127.
13. Földi M, Földi E, Strößenreuther C, et al. *Földi's textbook of lymphology: For physicians and lymphedema therapists*. München: Elsevier, 2012.
14. Zuther JE and Norton S. Complete decongestive therapy. In: Zuther JE and Norton S (eds) *Lymphedema management: The comprehensive guide for practitioners*. Stuttgart: Georg Thieme Verlag, 2013, pp. 101–132.
15. Quinlan E, Thomas-MacLean R, Hack T, et al. The impact of breast cancer among Canadian women: disability and productivity. *Work* 2009; 34(3): 285–296.
16. Boyages J, Kalfa S, Xu Y, et al. Worse and worse off: the impact of lymphedema on work and career after breast cancer. *SpringerPlus* 2016; 5: 657–658.
17. Peugniez C, Fantoni S, Leroyer A, et al. Return to work after treatment for breast cancer: single center experience in a cohort of 273 patients. *B Cancer* 2011; 98: E69–E79.
18. Babu BV, Swain BK and Rath K. Impact of chronic lymphatic filariasis on quantity and quality of productive work among weavers in an endemic village from India. *Trop Med Int Health* 2006; 11(5): 712–717.
19. Bifulco G, De Rosa N, Tornesello ML, et al. Quality of life, lifestyle behavior and employment experience: a comparison between young and midlife survivors of gynecology early stage cancers. *Gynecol Oncol* 2012; 124(3): 444–451.
20. Moffatt CJ, Franks PJ, Doherty DC, et al. Lymphoedema: an underestimated health problem. *QJM* 2003; 96(10): 731–738.
21. World Health Organization. *ICF: International classification of functioning, disability and health*. Geneva: World Health Organization, 2001.
22. Schreuer N, Rimmerman A and Sachs D. Adjustment to severe disability: constructing and examining a cognitive and occupational performance model. *Int J Rehabil Res* 2006; 29(3): 201–207.
23. Duijts S, Spelten E and Verbeek J. Behavioral determinants of employment status in cancer patients. In: Mostofsky DI (ed.) *The handbook of behavioral medicine*, vol. 1–2. Chichester: John Wiley & Sons, 2014, pp. 827–849.
24. Yin RK. *Case study research: Design and methods*. 5th ed. Thousand Oaks, CA: SAGE, 2014.
25. Microsoft Skype, 2017, <https://www.skype.com/en/>
26. Sun Y and Armer JM. A nurse's twenty-four-year journey with breast cancer-related lymphedema. *Work* 2019; 63(1): 21–31.
27. Ecamm Network, 2017, <http://www.ecamm.com/mac/call-recorder/>
28. Dedoose Version 7.0.23. Web application for managing, analyzing, and presenting qualitative and mixed-method research data, 2016, [www.dedoose.com](http://www.dedoose.com).
29. Glaser BG and Strauss AL. *The discovery of grounded theory: Strategies for qualitative research*. New York: Aldine de Gruyter, 1999.
30. Glaser BG and Strauss AL. *The discovery of grounded theory: Strategies for qualitative research*. Chicago, IL: Aldine Publishing Co, 1967.
31. Vassard D, Olsen MH, Zinckernagel L, et al. Psychological consequences of lymphoedema associated with breast cancer: a prospective cohort study. *Eur J Cancer* 2010; 46(18): 3211–3218.
32. Chachaj A, Malyszczak K, Pyszel K, et al. Physical and psychological impairments of women with upper limb lymphedema following breast cancer treatment. *Psychooncology* 2010; 19(3): 299–305.
33. Pinto M, Gimigliano F, Tatangelo F, et al. Upper limb function and quality of life in breast cancer related lymphedema: a cross-sectional study. *Eur J Phys Rehabil Med* 2013; 49(5): 665–673.
34. Pyszel A, Malyszczak K, Pyszel K, et al. Disability, psychological distress and quality of life in breast cancer survivors with arm lymphedema. *Lymphology* 2006; 39(4): 185–192.
35. Smoot B, Wong J, Cooper B, et al. Upper extremity impairments in women with or without lymphedema following breast cancer treatment. *J Cancer Surviv* 2010; 4: 167–178.
36. Fu MR and Rosedale M. Breast cancer survivors' experiences of lymphedema-related symptoms. *J Pain Symptom Manage* 2009; 38(6): 849–859.
37. Passik SD and McDonald MV. Psychosocial aspects of upper extremity lymphedema in women treated for breast carcinoma. *Cancer* 1998; 83: 2817–2820.
38. Taghian NR, Miller CL, Jammallo LS, et al. Lymphedema following breast cancer treatment and impact on quality of life: a review. *Crit Rev Oncol Hematol* 2014; 92(3): 227–234.
39. Ussher JM, Sandoval M, Perz J, et al. The gendered construction and experience of difficulties and rewards in cancer care. *Qual Health Res* 2013; 23(7): 900–915.
40. Pritlove C, Safai P, Angus JE, et al. “It's Hard Work”: a feminist political economy approach to reconceptualizing “Work” in the cancer context. *Qual Health Res* 2019; 29: 758–773.
41. Hemmingsson H and Jonsson H. An occupational perspective on the concept of participation in the international classification of functioning, disability and health—some critical remarks. *Am J Occup Ther* 2005; 59(5): 569–576.
42. Frazier LM, Miller VA, Horbelt DV, et al. Comparison of focus groups on cancer and employment conducted face to face or by telephone. *Qual Health Res* 2010; 20: 617–627.
43. Tiedtke C, Donceel P, Knops L, et al. Supporting return-to-work in the face of legislation: stakeholders' experiences with return-to-work after breast cancer in Belgium. *J Occup Rehabil* 2012; 22(2): 241–251.
44. van Muijen P, Weevers NL, Snels IA, et al. Predictors of return to work and employment in cancer survivors: a systematic review. *Eur J Cancer Care* 2013; 22(2): 144–160.
45. Blinder VS, Murphy MM, Vahdat LT, et al. Employment after a breast cancer diagnosis: a qualitative study of ethnically diverse urban women. *J Community Health* 2012; 37(4): 763–772.
46. Carlsen K, Jensen AJ, Rugulies R, et al. Self-reported work ability in long-term breast cancer survivors. *Acta Oncol* 2013; 52(2): 423–429.
47. Fantoni SQ, Peugniez C, Duhamel A, et al. Factors related to return to work by women with breast cancer in northern France. *J Occup Rehabil* 2010; 20(1): 49–58.
48. Hakanen JJ and Lindbohm ML. Work engagement among breast cancer survivors and the referents: the importance

- of optimism and social resources at work. *J Cancer Surviv* 2008; 2(4): 283–295.
49. Mujahid MS, Janz NK, Hawley ST, et al. The impact of sociodemographic, treatment, and work support on missed work after breast cancer diagnosis. *Breast Cancer Res Treat* 2010; 119(1): 213–220.
50. Tiedtke C, de Rijk A, Donceel P, et al. Survived but feeling vulnerable and insecure: a qualitative study of the mental preparation for RTW after breast cancer treatment. *BMC Public Health* 2012; 12: 538.
51. Ahn E, Cho J, Shin DW, et al. Impact of breast cancer diagnosis and treatment on work-related life and factors affecting them. *Breast Cancer Res Treat* 2009; 116(3): 609–616.
52. Hoving JL, Broekhuizen ML and Frings-Dresen MH. Return to work of breast cancer survivors: a systematic review of intervention studies. *BMC Cancer* 2009; 9: 117.
53. Short PF, Vasey JJ and Tunceli K. Employment pathways in a large cohort of adult cancer survivors. *Cancer* 2005; 103(6): 1292–1301.