

WOMEN AT WORK WITH BREAST CANCER-RELATED LYMPHOEDEMA

Mei R.Fu

Abstract

Background: Little attention has been given to the impact of lymphoedema on breast cancer survivors' work experience. **Aims:** To describe the experience of work of breast cancer survivors with lymphoedema. **Methods:** A descriptive phenomenological method was used. Sixty-six in-depth interviews were completed with 22 participants in the United States. **Results:** Three essential themes illuminating the meaning of working for breast cancer survivors with lymphoedema emerged, namely: having a visible sign of disability or a need for help; having physical limitations that made some women handicapped, while others felt inconvenienced; and, finally, some women had constant worries while others felt fortunate. **Conclusions:** Women endured emotional distress at work. Women whose jobs required heavy lifting and constant use of the affected limb, suffered profoundly from the physical and functional impact of having lymphoedema. Future research should focus on interventions that help employers to understand breast cancer survivors with lymphoedema and improve their working conditions. **Declaration of interest:** This study was supported by an NIH grant (F31 NR0785); a grant from NYU School of Education and NYU Pless Center for Nursing Research.

Key words

Lymphoedema
Breast cancer
Work
Emotional distress

Approximately 20% of the two million breast cancer survivors in the United States have developed lymphoedema and all women who have breast cancer treatment are at risk of developing lymphoedema in their lifetime (Armer et al, 2004; Schultz, et al, 2005). As a serious long-term complication from breast cancer treatment, lymphoedema or persistent swelling is caused by chronic accumulation of lymph fluid in the affected arm or hand due to disruption or interruption of the lymphatic system (Brennan and Miller, 1998; Foeldi et al, 2003). While the

impact of lymphoedema on breast cancer survivors' quality of life has been well acknowledged (Pyszel et al, 2006; Velanovich and Szymanski, 1999), little attention has been paid to the impact of lymphoedema on breast cancer survivors' experience of work.

More and more women have returned to or maintained work after their diagnosis or treatment. This is vital for a survivor's quality of life (Anderson and Armstead, 1995).

Few studies have investigated the experience of work for breast cancer survivors with lymphoedema. Moffatt et al (2003) found that oedema from lymphoedema caused time off work in more than 80% of their 228 lymphoedema participants, and affected employment status in 9%. A decade ago, Carter (1997) briefly mentioned in her qualitative study that lymphoedema interfered with some breast cancer survivors' work involving

heavy lifting, gripping, holding and fine motor dexterity. To date, no research has explicitly investigated the impact of lymphoedema on breast cancer survivors' experience of work.

There has been an increase in the number of women who are employed when they are diagnosed with and treated for breast cancer (Maunsell et al, 2004). More and more women have returned to or maintained work after their diagnosis or treatment. This is vital for a survivor's quality of life (Anderson and Armstead, 1995). For some breast cancer survivors, their earnings from work are necessary to meet basic needs and facilitate a return to the daily activities of life. While for other women, work after breast cancer is an important measure of recovery from the disease and a positive step towards the future (Maunsell et al, 2004). In addition, work provides women with companionship. The known impact of lymphoedema on impaired physical function and disrupted interpersonal relationships (Carter, 1997; Radina and Armer, 2001) makes it important to understand the impact of lymphoedema on breast cancer

Mei R Fu is Assistant Professor at the College of Nursing, New York University, New York

survivors' experiences at work. The aim of this study was to describe these experiences.

Methods

The study reported here is derived from three larger studies on breast cancer survivors' intentions of managing lymphoedema, that is, their intentional efforts and actions (Fu, 2005) within diverse racial and ethnic groups (e.g. White, African-American and Chinese American).

A purposive sampling technique was employed (Fu, 2005) to recruit participants who met the inclusion criteria: (a) being 18 years of age or older; (b) having completed surgical treatment for breast cancer at least three months before enrolling in the study; and (c) having had a diagnosis of lymphoedema for at least one month prior to enrolling in the study. Following approval to conduct the studies from two universities' institutional review boards, a total of 34 participants were recruited in a midwest state (12 participants) in 2002, and east coast metropolitan areas (22 participants) of the United States from 2005 to 2007. Informed consent was secured from all the participants. Three in-depth interviews were conducted with each participant, a total of 102 interviews were completed. Each interview lasted from 70 to 140 minutes and was recorded using a digital audio-system. All the interviews were professionally transcribed and checked for accuracy.

For the study reported here, data were analysed from a specific sub-sample of 22 women who were employed. Among the 22 women, seven were having intensive lymphoedema therapy for the exacerbations of lymphoedema, such as sudden increased swelling following cellulitis, severe pain, soreness and fatigue in the affected limb or sudden decreased function of the affected limb; 10 had jobs that did not require heavy lifting and frequent use of their affected arms and hands (such as teacher, cytological technologist, transcriber, office manager, or psychologist); seven women had jobs that required heavy lifting or constant use of their affected arms and hands (such

as electrocardiogram [ECG] technician, nurse aid, hairdresser, data processor, factory worker, waitress, or pathological lab technician); and five women had jobs that required constant typing or filing of documents (such as administrative aid or office worker). *Table 1* provides detailed information of the participants.

Data gathering and analysis were guided by a descriptive phenomenological method (*Table 2*) developed by the principal investigator

(Fu, 2005). To study the experience of work for breast cancer survivors with lymphoedema, all participants were given at least three opportunities during each interview to spontaneously report major events related to their work. The participants were asked to answer the following interview questions:

- ▶▶ What was it like for you to have lymphoedema at work?
- ▶▶ How have things changed with regard to your work since you have had lymphoedema?

Table 1
Characteristics of the participants

Total sample		N=22	
Ethnicity		n	
White		8	
African American		7	
Chinese American		7	
Age (years)	Mean	Range	
Total sample	53	42–65	
White	56	46–62	
African American	51	42–65	
Chinese American	51	44–64	
Time since lymphoedema diagnosis	Mean	Range	
Total sample	3 years 1 month	2 months–9 years	
White	3 years 7 months	1 year 4 months–9 years	
African American	2 years	2 months–5 years	
Chinese American	3 years 4 months	1 year–7 years	
Time since breast cancer surgeries	Mean	Range	
Total sample	4 years 8 months	1 year 2 months–14 years	
White	5 years 4 months	2 years 10 months–14 years	
African American	3 years 8 months	8 months–7 years	
Chinese American	4 years 9 months	1 year 2 months–9 years	
Occupations	White	African American	Chinese American
Job requiring less heavy lifting and less use of the affected arm and hand	6	3	1
Job requiring repeated heavy lifting or constant use of the affected arm and hand	1	1	5
Job requiring constant typing or filing of documents	1	3	1

General probes were also used during the interviews, such as: 'Please tell me more about that'; 'How did that make you feel?' and 'What else did you also do?' The data reported here were drawn from 66 interviews.

The fundamental activity of data analysis is the essence of experience which has been defined by Husserl (1913) as 'essential universality' or 'essential generality' in individuals' experiences that 'can be exemplified intuitively in the data of experience, data of perception, [and] memory'. A descriptive data analysis method (Fu, 2005) was employed using strategies of 'description; comparing and distinguishing, collecting and counting, presupposing and inferring' (Husserl, 1913) in a reflective and intuitive way. Each idea was carefully analysed in every transcript. Each essence of the women's experience was differentiated, compared, and summarised. Examples were carefully selected to demonstrate the essential meanings of the experience (Fu, 2005; Porter, 1998). The essences of the experience of work for these women were fashioned into essential themes illuminating the meaning of the experience.

The credibility of findings, in terms of integrity and accuracy (Parse, 2001), was supported through the investigator's discussions with participants and two doctorally prepared expert researchers who considered the data analysis valid. The investigator finally discussed the findings by integrating relevant literature. In line with Husserl's (1913) position that 'each has his place whence he sees the

things that are present', the author also invited readers to appraise the credibility of findings on the basis of their own practical experience (Porter, 1999).

Findings

With regard to the experience of work for breast cancer survivors with lymphoedema, three essential themes illuminating the meaning of the experience were developed:

- ▶▶ Having a visible sign: disability versus a need for help
- ▶▶ Having physical limitations: being handicapped versus the inconvenience
- ▶▶ Worrying constantly versus feeling fortunate.

Having a visible sign: disability versus a need for help

The women were all aware of their visible signs of lymphoedema. As Ms DA stated, 'Lymphoedema is so physical that everybody can see it. It's a reminder every minute of the day that I have lymphoedema.' For the women, the visible signs included enlarged swollen arms or puffy swollen hands or the compression sleeves, gloves, wraps, or bandages they wore. As Ms KY, a cytological technologist described, 'An analogy would be if you saw someone in a wheelchair; you know that there is something wrong with that person. You see somebody walking around with one arm bigger than the other or wearing a compression sleeve, you know immediately that something is wrong with this person.' While working with the visible signs of lymphoedema, the women encountered different treatment from their colleagues or employers.

For all the women, the visible signs of lymphoedema signalled that they had 'some kind of disability'. As Ms AH, a data processor in a metropolitan company said, 'At work, I always wear a long sleeve so that people will not see my arm with the compression sleeve on. You never know what people think. They might think that I am disabled or I have something contagious. So, I try to cover my arm at work. I do not want people to think that there is something wrong with this arm.' Ms DM, a psychologist said, 'Because I have to wear the compression sleeve at work, I do not want people to think that there is something wrong with me. Mainly, I've tried to wear something like this [pointing to the long-sleeve black jacket she's wearing] at work, so, it [the compression sleeve] would not be that obvious to my clients.'

For women who could not cover the swelling in their affected hands, the visible signs brought more distress at work. Ms EP was working as a waitress at a large restaurant. For her, having the visible sign of a swollen hand produced constant distress. As she described, 'My boss constantly reminded me that I'd better cover my hand well so that our customers would not be scared. I understand that people might lose their appetite if they see my swollen hand or they might think something worse. Every time I reminded myself to only use the other hand to put food on the table so that I don't give people the chance to compare [my hands]. I am really stressed out to be reminded everyday, as if I had something very disgusting.'

For some women whose jobs involved occasional heavy lifting, having the visible signs of lymphoedema signalled their need for help. Their compression sleeves had enabled them to ask for help without opening their mouths. Ms TB, a 64-year-old telephone operator said, 'Before [I had lymphoedema], I had to ask for help for lifting something heavy. When I came back to work wearing the [compression] sleeve, my co-workers asked me what the sleeve was for. I explained to them and they understood that I wasn't supposed to lift. So, when we need to move the heavy boxes, they see my sleeve and say, "Don't lift those

Table 2

Descriptive phenomenological method

Phases	Procedure
I	Prepare the study through reflection and phenomenological reduction
II	Gather data by conducting multiple interviews
III	Conduct a descriptive data analysis in a reflective and intuitive way that enables a description of the essence of experience
IV	Discuss the findings by integrating the bracketing knowledge and relevant literature

boxes. We will take care of them". So, somebody is lifting the boxes that I am supposed to without my asking. In a way, my sleeve has helped me to ask for help.' Similarly, Ms AL, an elementary school teacher said, 'Before my lymphoedema, I had to ask people to help to move the tables or books. It's hard to always ask for help. Sometimes, I ended up doing it all by myself. Now, with my [compression] sleeve and glove on, I don't need to ask for help. My co-workers say, "I will move the tables and books". My sleeve and glove signal silently my need for help.'

For some women, like Ms LW who was a pathology laboratory technician at a large metropolitan cancer centre, having the visible signs of lymphoedema signalled disability and the need for help, which brought more distress to daily work. As Ms LW described, 'When my co-workers saw my hand swell up, they tried to help me with the vertex machine. But, when Mr XX [my supervisor] saw them help me, he was very upset. He pointed to my swollen hand and said, "You'd better apply for disability since you can't do the job so that I can hire someone to do the job"'. Ms LW was severely distressed because she needed the job and did not want to apply for disability. For Ms LW, 'My [swollen] arm and hand is like an invoking sign that makes Mr XX yell and shout at me whenever he sees.' Ms WH, who worked at a clothing factory in China town, had a similar experience. For Ms WH, constant use of her arm and hand to sew on the sewing machine made her hand 'swell as a steamed bun'. Sometimes, her friends at the factory wanted to help her but her boss was very upset, yelling, 'When your hand is burst, I hope I will not see you again.' As a single mother with two children under the age of 15, Ms WH had to keep her job and just ignore the verbal abuse from her employer.

Having physical limitations: being handicapped versus the inconvenience

The women used the words 'handicapped', 'debilitating', 'disabled', 'limiting', 'bothersome', and 'inconvenient', to describe their experience of work with lymphoedema. For the women, having lymphoedema at work results in physical limitations on heavy lifting and frequent use of their affected arms

and hands. Depending on the nature of their jobs, their work experience with lymphoedema varied considerably.

For the women whose jobs required repeated heavy lifting or constant use of their affected limbs (seven out of 22), and whose jobs required constant typing and filing of documents (five out of 22), having physical limitations made them feel 'handicapped', 'disabled', or 'debilitated'. For example, as an ECG technician in a hospital, Ms JL's job required her to lift patients. As she described, 'I am handicapped by lymphoedema. I cannot lift my patients just using my right [non-affected] arm. I have to ask people to help me to lift

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patients. Often, people are busy with their own work and I have to wait. It can be very depressing for women like me in the working field.'

Ms LW's laboratory job involved repetitive movement of her affected arm and hand and required her to hold her arm in a fixed, steady position for extended periods of time, including times when her arm was subject to a significant vibratory stress. As she described, 'I felt disabled because of lymphoedema. Although I tried to use my left [non-affected] hand and arm as much as possible, a lot of my work in the lab needs both hands and arms. For example, every day I have to use a vertex machine to vibrate more than 50 samples. I have to use both hands to hold each sample tube while the vertex machine vibrates each sample for five minutes. After holding more than 50 samples for about 250 minutes of vibration, the swelling was worse and the pain, soreness, and fatigue in my right [affected] arm and hand were unbearable. Besides, I have to push and pull other heavy machines or objects

in the lab. Vibration, overuse of my arm and hand, and lifting or pushing heavy objects are risks that I have to avoid to prevent lymphoedema from getting worse. However, because of the nature of my job, I have been exposed to such risks every day. Although I have been going to physical therapy, the swelling, pain, soreness and fatigue have not reduced. Each day my swelling becomes worse and the symptoms are so intense. I have decided that as long as I can bear the swelling and symptoms, I will try my best to continue working as I need the medical insurance and income from my job.'

Ms KW was an administrative aide working for a state government in the west. Her job required constant typing or filing. For her, 'As I type all day long, by the end of each day I see my hand swell like freshly baked bread. My fingers cannot move any more. Although my boss does not say a word, I know that I have to finish my work, typing and filing. Otherwise, I might have been fired a long time ago. Sometimes I think that if I had another kind of job, I would not need to type this much, my swelling might go away and I would not feel so debilitated by the cancer.' Ms KW had been going to intensive lymphoedema treatment three times a week for 18 months since her lymphoedema diagnosis. She felt, 'the repetitive typing from my job makes my swelling out of control.'

For other women whose jobs only required occasional lifting (10 out of 22), although they had to 'rely on somebody to pick up the heavy things' and to 'wait for somebody to help to move the tables' at work, having physical limitations on heavy lifting just brought a little 'limitation', 'inconvenience' or 'bother' to their work. As Ms HM, a middle school teacher with more than seven years of lymphoedema said, 'Lymphoedema has very little impact on my job. My co-workers and staff understand my situation with breast cancer and lymphoedema and they are very supportive. Lymphoedema only limits me to do something like lifting. Occasionally, if there is a heavy box for me in the office, I will wait and let my colleagues bring it to me.' Ms KY,

a pathologist, also echoed, 'Nothing has really changed for my job with lymphoedema because I have a very sedentary job. I sit and look through the microscope. Even when I had my arm wrapped under lymphoedema treatment, I could still do my job because all I had to do was to look through the microscope and I could use my other hand to move the slides.'

Worrying constantly versus feeling fortunate

Having survived breast cancer, the women felt very 'grateful' and 'fortunate' to be alive. As Ms HL stated, 'I am just grateful that I am alive and have lymphoedema.' Yet, their work experience with lymphoedema invoked different states of emotions.

For women whose job required heavy lifting and constant use of their arms and hands, their work experience with lymphoedema brought them constant worries, especially for women whose supervisors or employers were neither understanding nor supportive. Ms LW had daily distress from the inappropriate yells and shouts from her supervisor and was scared that she would lose her job at any time. As Ms LW explained, 'Mr XX [my supervisor] did not understand my situation as a breast cancer survivor with lymphoedema. He was upset when I tried to explain to him the difficulties I had at work, such as holding the sample tube for vibration and pushing or pulling heavy objects. When he saw my swollen hand and arm getting worse, he yelled and shouted at me, saying, "you should just stay at home." I am scared that I will lose my job at any time.' Ms JE, a hairdresser, also expressed similar concerns, saying, 'I am afraid that some day my boss will just let me go home when she sees my arm is getting bigger and bigger.' Ms EP, the waitress, echoed a similar experience, 'It's the time after time that you are reminded by your boss that you have something wrong with your arm which puts you in a constant worry about your job security. You can get distressed.'

The women were also worried that their work would worsen their lymphoedema. As Ms KW said, 'I am worried all the time that my job will make the swelling get worse and worse and

out of control because I am constantly typing and filing. Sometimes, I think it is my work that makes the therapy not work. I am so frustrated not seeing the progress of the therapy.' Ms AH also expressed, 'As I type each day and see my hand swell up by the middle of the day, I cannot stop worrying that some day I might no longer be able to use my arm and hand if I continue my job. I am worried about my future.'

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Some women were also concerned that their work would make their cancer reoccur. As Ms DA stated, 'When I type for a long time and look at my puffy hand, I cannot stop thinking, "this [my job] not only has made my lymphoedema out of control but maybe some day it [my job] will also bring back my cancer.'" Lymphoedema is a constant reminder of my cancer. You cannot really forget that you have had cancer because you are reminded every day.' Ms MC worked at a Chinese food company in Chinatown. She also echoed, 'I have to carry a lot of heavy boxes of [Chinese] dumplings for my work. Even if I don't care about the ugly appearance of my puffy arm, I am constantly worried that my cancer will be back if my arm gets bigger and bigger.'

Women (10 out of 22) whose job required no heavy lifting or infrequent use of the affected arm or hand, experienced little impact of lymphoedema on their work. They 'felt very fortunate' that their cancer and lymphoedema had not changed their ability to work. Ms DF, an office supervisor at a metropolitan company said, 'Nothing has really changed with my job, even when I had my arm wrapped. I have a very sedentary job. My staff are understanding and supportive. In a way, I had less impact [from lymphoedema]

on my job than at home. I am fortunate here. I know there are people who are nurses or working at grocery stores, they have lymphoedema, they have to lift patients and pick up things all the time. Lymphoedema is really a debilitating factor for them. I have been very fortunate in my position.' Ms KY, the pathologist also echoed, 'I feel fortunate that I can still work without worrying about if I have to lift some heavy things or use my [affected] hand all the time. Imagine if I was a factory worker... I feel very fortunate.'

Discussion

It cannot be claimed that the essences of the experience drawn from these 22 women represent the experiences at work of all breast cancer survivors with lymphoedema. Future studies in different geographical areas and occupations are needed. Despite its limitations, findings of the study offer insight into the participants' daily arduous struggle at work with lymphoedema, especially for women whose jobs required heavy lifting and constant use of the affected limb.

Carter (1997) briefly mentioned that lymphoedema interfered with some breast cancer survivors' work involving heavy lifting, gripping, holding and fine motor dexterity. This study confirmed that the impaired physical function from lymphoedema not only handicapped the women in performing their work in this respect, but also brought a great deal of daily emotional distress. Lymphoedema, as the visible sign of disability, not only visually separated the women from healthy workers, but also made them the target for blame. The women's constant worries about their job performance and security, worsening of lymphoedema and cancer reoccurrence, placed them in a distressful emotional state. Previous studies (Carter, 1997; Greenslade and House, 2006) revealed that breast cancer survivors with lymphoedema experienced a combination of emotions of abandonment, loss, sadness, frustration, and anger because of the lack of information and effective lymphoedema treatment. This current study has revealed a fresh face of the distress and worries of the working lives of breast cancer survivors with lymphoedema.

It is important to note that the majority of women (12 out of 22) whose jobs involved heavy lifting and constant use of the affected arm and hand were from either African American or Chinese American groups, who needed their jobs as a source of financial income or medical insurance. These women suffered profoundly the physical and functional impact of lymphoedema on their work, and they had to endure constant emotional distress created by their supervisors or employers who had no understanding of breast cancer survivors with lymphoedema. Future studies should focus on the impact that lymphoedema can have on the working lives of breast cancer survivors from minority ethnic groups, and on the interventions necessary to improve the conditions in which they work.

Conclusions

Findings of this study provide new information and insights regarding the experiences of work of breast cancer survivors with lymphoedema. The study suggests that returning to work, maintaining employment, or time off from work are important indicators for measuring the impact of lymphoedema. However, such indicators might not be able to capture the physical, functional, emotional impact of lymphoedema on breast cancer survivors who are struggling to maintain their day-to-day work. Although work provided a primary source of financial income and medical insurance, it also became the primary source of distress and worry for the women. The women's experiences can guide clinicians to explore the meaning of work in the lives of breast cancer survivors and encourage the development and use of programmes aimed at enabling employers to understand the impact of lymphoedema on breast cancer survivors. JL

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Key points

- » There has been an increase in the number of women who are employed when they are diagnosed with and treated for breast cancer; more and more women have returned to or maintained work after their breast cancer diagnosis or treatment.
- » The known impact of lymphoedema on impaired physical function and disrupted interpersonal relationships makes it important to understand the impact of lymphoedema on breast cancer survivors' experience of work.
- » Breast cancer survivors, especially those whose jobs required heavy lifting and constant use of their affected arms and hands, suffered profoundly from the physical and functional impact of lymphoedema on their work, and they had to endure constant emotional distress created by their supervisors or employers who had no understanding concerning breast cancer survivors with lymphoedema.
- » Findings of the study can guide clinicians to explore the meaning of work in the lives of breast cancer survivors and encourage the development and use of programmes aimed at enabling employers to understand the impact of lymphoedema on breast cancer survivors.