CANCER SURVIVORS’ VIEWS OF LYMPHOEDEMA MANAGEMENT

Mei R. Fu

Abstract

Background: Many clinicians recognise the importance of the patient’s role in treating and managing lymphoedema and that optimal outcomes depend on patients’ compliance to treatment, or a prescribed daily lymphoedema care regimen. Such a widespread belief can be called a ‘compliance paradigm’. Aims: To ascertain whether breast cancer survivors with lymphoedema have the same concept of compliance as clinicians to characterise their experiences. Methods: Using a descriptive phenomenological method, 34 participants were recruited and 102 interviews completed. Results: The findings of the study reveal that, from the perspective of breast cancer survivors, managing lymphoedema is broader than compliance to treatment. The women actively structured their lives to make lymphoedema management feasible by incorporating it into a daily routine. The study offers an alternative insight into the compliance approach to lymphoedema management and it is important for researchers and clinicians to be aware that breast cancer survivors do not consider compliance to treatment as part of their daily lymphoedema care. Conclusions: In research and practice, it may be more appropriate to assess the presence or absence of breast cancer survivors’ intentions, effective and ineffective strategies, and barriers to effective strategies. Conflict of interest: None.

Key words
Breast cancer survivors
Lymphoedema management
Patient compliance
Phenomenology

The management of lymphoedema is a major healthcare challenge, as a cure for this chronic condition has yet to be found (Fu and Rosedale, 2009). Complete decongestive therapy (CDT) (also known as comprehensive decongestive therapy or complex physical therapy) has become the standard management regimen for treating lymphoedema in the US. CDT typically involves manual lymph drainage (MLD), multilayer compression bandaging, remedial exercise, meticulous skin care, elastic compression garments and patient education (Megens and Harris, 1998; National Lymphoedema Network [NLN], 2010).

CDT requires patients to make a daily commitment to alleviate swelling and symptoms as well as preventing acute exacerbations by using external compression (sleeve, glove, wrap, bandage or pump), performing remedial exercise and self-lymph massage, and conducting skin care (Davis, 1998; Rockson et al., 1998). Clinicians and researchers have recognised the importance of the patient’s role in treating and managing lymphoedema and that management depends on patient compliance with treatment or a prescribed daily lymphoedema care regimen (Carter, 1997; Passik and McDonald, 1998; Paskett and Stark, 2000).

The belief that patients should comply with what they are instructed to do is known as the compliance paradigm and research into this concept has produced valuable insights regarding post-breast cancer lymphoedema, especially its impact on survivors’ lives and chronicity. For example, research discovered that increased limb volume or swelling does have a negative impact on patients’ quality of life (Velanovich and Szymanki, 1999; Paskett and Stark, 2000; Pyszel et al., 2006).

However, these studies rarely capture the survivors’ experiences of managing lymphoedema in their everyday lives. It is unknown whether survivors use the same concept of compliance as clinicians/researchers to characterise their experiences.

Each descriptive phenomenological study attempts to reveal the essence of an experience and suggests ways
to enhance the empirical validity of relevant concepts (Husserl, 1962). A descriptive phenomenological study of breast cancer survivors’ experiences of managing lymphoedema could expand the knowledge base around compliance and how this impacts on treatment. Therefore, it was important to explore breast cancer survivors’ perceptions and describe their daily experiences of managing lymphoedema. The aims of the study were to:

- Describe breast cancer survivors’ experiences of managing lymphoedema
- Identify effective strategies for managing lymphoedema and any potential barriers to these.

**Method**

**Design**

A qualitative design with a descriptive phenomenological method was used. The philosophy behind the study was based on certain assumptions grounded in Husserlian descriptive phenomenology explicated in his book (Husserl, 1962). These are summarised in Table 1.

The author designed the three projects to investigate breast cancer survivors’ experience of managing lymphoedema within diverse racial and ethnic groups (i.e. white, African-American and Chinese American). The main aim of the projects was to delineate the three groups’ overall experiences of managing lymphoedema. The essential intentions of the white American sample when managing lymphoedema were reported elsewhere (Fu, 2005) and included preventing lymphoedema from getting worse, preparing to live with lymphoedema and integrating the care of lymphoedema into their daily life.

The study reported here uses data from all three ethnic groups to focus on breast cancer survivors’ experiences of managing lymphoedema, including how they have followed or complied to a prescribed daily lymphoedema care regimen.

**Recruitment of participants**

After the institutional review boards University had approved the study (the Health Sciences Center Institutional Review Board of Human Subjects at University of Missouri and University Committee on Activities Involving Human Subjects at New York), invitations were distributed to potential participants by oncologists, nurses and physical therapists. The author met with each woman to confirm the study criteria. Consent was obtained from each participant. Confidentiality was ensured through a coding system and interviews were conducted in private settings. The names used to report the findings are pseudonyms.

**Sample and participants**

A purposive sampling technique was employed (Fu, 2005) to enrol women who met the eligibility criteria:

- Being 18 years of age or older
- Having completed surgical treatment for breast cancer at least three months before enrolling in the study
- Having had a medical diagnosis of lymphoedema for at least one month before enrolling in the study.

Table 2 provides demographic information about the participants.

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### Table 1

**Philosophical underpinnings and assumptions of the study (Husserl, 1962)**

<table>
<thead>
<tr>
<th>Essential beliefs of Husserlian descriptive phenomenology</th>
<th>Assumptions of the study</th>
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<tbody>
<tr>
<td>‘Natural knowledge begins with experience and remains within experience’ (Husserl, 1962; p. 45)</td>
<td>Breast cancer survivors’ experiences of managing lymphoedema emerge from the experiences in which women interact with the condition of having lymphoedema</td>
</tr>
<tr>
<td>‘Every experience... has intentionality’ (Husserl, 1962; p. 222)</td>
<td>Breast cancer survivors can purposefully reflect on their experience of having lymphoedema</td>
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<tr>
<td>‘Each individual event has its essence that can be grasped in its eidetic purity’ (Husserl, 1962; p. 104)</td>
<td>Breast cancer survivors can purposefully undertake efforts and actions linked to their perceptions about the conditions of having lymphoedema</td>
</tr>
<tr>
<td></td>
<td>Breast cancer survivors’ intentional efforts were viewed in the study as their intentions of managing lymphoedema</td>
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</table>

Husserl (1962) defined essence of experience as the ‘essential universality’ (p. 47) or ‘essential generality’ (p. 53) in an individual’s experience that ‘can be exemplified intuitively in the data of experience’ (p. 50). Detailing the essence of an experience can be achieved through the description of intentional efforts (or intention) and actions (or strategies) undertaken by the breast cancer survivors who shared their experiences.
In a phenomenological study, the adequacy of the sample size is determined by the quality of the data, that is, recruitment of participants should continue until similar data emerge or once participants repeat each other when describing their experiences (Morse, 1986). Strong similar data emerged when the author finished the interview of the 28th participant. To ensure that any important information would not be missed, the author continued recruiting and interviewed two extra participants in each ethnic group.

Data collection
The author completed a total of 102 interviews from 2002–2007, that is, three in-depth interviews with each participant. Each interview lasted from 70–140 minutes and was recorded using a digital audio-system. All the interviews were professionally transcribed and checked for accuracy.

To study breast cancer survivors’ experiences of managing lymphoedema, each participant was given at least three opportunities to relate her perceptions and actions during each interview. The participants were asked to answer the broader question: ‘What is it like for you to take care of your lymphoedema?’ as well as further specific questions:

- “How have you tried to take care of your lymphoedema?”
- “How have you worked out the details of taking care of your lymphoedema?”
- “How have you followed the instructions of taking care of your lymphoedema given by your healthcare providers?”

General probing questions 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?’

Data analysis
A descriptive data analysis method with intuitive reflections was employed (Fu, 2005; Fu and Rosedale, 2009) and specific data analysis procedures are summarised in Table 3. Through the discovery of recurring themes and remaining close to the data by matching as many of the themes to the participants’ actual words, a fuller description of how women managed their lymphoedema was provided. For example, given the phrases ‘I’m making it work for me’, or ‘I’m trying to make it feasible’, the researcher has to choose the most representative description. In this case, after discussion with the qualitative experts, the author decided to use the phrase ‘Making lymphoedema care feasible’ to describe the primary experience.

Findings
The essential themes that emerged from the breast cancer survivors’ experience of ‘making lymphoedema care feasible’ were based upon their realisations that taking care of lymphoedema was a ‘lifetime commitment’ because ‘lymphoedema won’t go away’ and ‘lymphoedema can get worse’.

Three intentions that summed up the experience of living with lymphoedema were (Table 4):

- Making conscious decisions about new-fangled limitations (i.e. those limitations that emerged with the experience of lymphoedema)
- Making daily care feasible
- Incorporating lymphoedema care into a daily routine.

Making conscious decisions about new-fangled limitations
To prevent lymphoedema exacerbation the women were instructed to avoid heavy lifting or overuse of their affected limbs. Initially, some women would forget or ignore the fact that they had lymphoedema and would continue doing what they used to do. As Ms Rita, a 53-year-old white woman, described it:

<table>
<thead>
<tr>
<th>Ethnicity</th>
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<tbody>
<tr>
<td>White</td>
<td>10</td>
</tr>
<tr>
<td>African American</td>
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<tr>
<td>Chinese American</td>
<td>13</td>
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<table>
<thead>
<tr>
<th>Age (years)</th>
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<tbody>
<tr>
<td>Mean</td>
<td>55</td>
</tr>
<tr>
<td>Range</td>
<td>35–86</td>
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<table>
<thead>
<tr>
<th>Duration of lymphoedema</th>
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<tbody>
<tr>
<td>Mean</td>
<td>Five years and five months</td>
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<tr>
<td>Range</td>
<td>Two months to 23 years</td>
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<table>
<thead>
<tr>
<th>Duration of breast cancer diagnosis</th>
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<tbody>
<tr>
<td>Mean</td>
<td>Seven years</td>
</tr>
<tr>
<td>Range</td>
<td>18 months to 23 years</td>
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<table>
<thead>
<tr>
<th>Types of breast surgery</th>
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<tbody>
<tr>
<td>Lumpectomy</td>
<td>9</td>
</tr>
<tr>
<td>Modified or partial mastectomy</td>
<td>7</td>
</tr>
<tr>
<td>Mastectomy</td>
<td>18</td>
</tr>
<tr>
<td>Lymph nodes removed</td>
<td>32</td>
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</table>

<table>
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<tr>
<th>Numbers who had chemotherapy</th>
<th></th>
</tr>
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<tbody>
<tr>
<td></td>
<td>25</td>
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<tr>
<th>Numbers who had chemotherapy radiation</th>
<th></th>
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<tbody>
<tr>
<td></td>
<td>24</td>
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<th>Numbers who had radiation and chemotherapy</th>
<th></th>
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<tbody>
<tr>
<td></td>
<td>12</td>
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</table>

Table 2
Characteristics of participants

In a phenomenological study, the adequacy of the sample size is determined by the quality of the data, that is, recruitment of participants should continue until similar data emerge or once participants repeat each other when describing their experiences (Morse, 1986). Strong similar data emerged when the author finished the interview of the 28th participant. To ensure that any important information would not be missed, the author continued recruiting and interviewed two extra participants in each ethnic group.

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Making conscious decisions about new-fangled limitations
To prevent lymphoedema exacerbation the women were instructed to avoid heavy lifting or overuse of their affected limbs. Initially, some women would forget or ignore the fact that they had lymphoedema and would continue doing what they used to do. As Ms Rita, a 53-year-old white woman, described it:
At times, I forget that I had it. I moved my furniture around and lifted the heavy stuff that I used to. Then, I suffered the swelling arm, burning and pain.

Ms Rose, a 79-year-old African-American woman, agreed:

At the very beginning, I thought, ‘if I ignore or neglect it [lymphoedema], I should be better’. So, I kept doing what I was not supposed to do. My arm and hand became bigger and heavier. I learned my lesson.

The exacerbation of swelling and worsening of other symptoms forced these two women to acknowledge limitations that they never imagined they had.

Realising that they could no longer do what they used to do was a ‘big hit’ to most of the women. Ms Lou, a 63-year-old African-American woman, found that ‘even carrying a laundry basket and scrubbing the bathtub became unbearable’. The women found that daily chores involving heavy lifting (or carrying food trays), repeated use of the hand or arm (typing, scrubbing, painting, ironing or vacuuming), manually laborious work (sewing or making dumplings) exacerbated swelling and the symptoms of heaviness, pain, burning, limited limb movements and fatigue. Activities of daily living such as ‘stirring food’ or ‘being unable to wrap my arm’ became the source of intense frustration and an unwelcome reminder of their cancer: Facing these new-fangled limitations, the women tried to make conscious decisions.

The most effective strategies that the women used was to ‘give up’ or ‘let go’ of what they could. Ms Lam, a 43-year-old Chinese woman, and Ms Jane, a 63-year-old white woman, used to enjoy putting possessions in different storage boxes or helping others alter their furniture. After several difficulties with worsening lymphoedema symptoms, they made a decision that they had to ‘give up doing storage, cutting wood or carpet, sorting things, and fixing furniture for family members and friends’.

Similarly, Ms Anna, a 57-year-old white woman, noticed increased swelling and pain in her affected arm each time after she finished her cross-stitching. This made her consciously decide to ‘let go’ of a hobby that she had enjoyed since her childhood. In another example, Ms Johnson, a 65-year-old white woman, used to enjoy using heavy iron skillets to cook, however, since she noticed increased swelling and pain she had made the decision to instead ‘buy the lightweight skillets’.

Some women gave up leisure activities, such as sunbathing, hot-tub, whirlpool, rafting, boating or outdoor swimming. Giving up or ‘letting go’ of ‘what was normal and enjoyable’ for them in the past was hard because it involved a conscious decision every time. However, giving up these activities was still an effective and feasible strategy for coping with their limitations.

Asking for help was another effective strategy for some women. Those who had a good support system of family, friends and coworkers found it easier to use this strategy. Ms Michelle, a 58-year-old white woman, used to be the ‘sole chef’ at family dinners during the holidays. In the first year of her lymphoedema diagnosis, she continued preparing meals for Thanksgiving and Christmas. However, after each dinner, her lymphoedema would ‘flare up’ with uncontrollable swelling and multiple symptoms and she was forced to ask for help:

Since then when I prepare family dinners, I always have to ask my daughters to cut vegetables and meat. I have to remember to ask my son or my husband to lift big pans off the stove. I have to make a plan for them to help.

Ms Barb, a 54-year-old white high school teacher, finally decided to ask her colleagues to help with heavy boxes:

I really appreciate everything my coworkers have done for me. Now, I don’t even need to ask for help. They always say, ‘Don’t worry, we’ll do it’.

However, widowed or single women often found it difficult or frustrating to use this strategy for household chores, wrapping their limbs or moving furniture. For example, Ms Marnie, a 48-year-old African-American woman, described having to wait for help:

Table 3
Specific data analysis procedures

<table>
<thead>
<tr>
<th>Steps</th>
<th>Descriptions</th>
</tr>
</thead>
<tbody>
<tr>
<td>I</td>
<td>Reading the transcripts several times to gain a broad understanding of the text</td>
</tr>
<tr>
<td>II</td>
<td>Meeting with a group of qualitative researchers who reviewed transcripts, identified key quotations and discussed key codes related to the research question</td>
</tr>
<tr>
<td>III</td>
<td>Combining the coded quotations into one file and confirming the accuracy of the code and quotation</td>
</tr>
<tr>
<td>IV</td>
<td>Carefully reading quotation files with the group and identifying major themes by putting key coded quotations together for each research question</td>
</tr>
<tr>
<td>V</td>
<td>Meeting with the group, reviewing major themes together, and engaging in active dialogue to resolve any discrepancies</td>
</tr>
<tr>
<td>VI</td>
<td>Reviewing the transcripts and validating the structure of themes alongside interview data</td>
</tr>
</tbody>
</table>
I had to wait for a week to have my brother-in-law come to move my couch. It is frustrating but I have to be patient.

An unsupportive working environment created by employers’ misunderstanding was the most frustrating barrier to this strategy of asking for help for the women whose job required manual work. Describing her frustration, Ms Wong, a 47-year-old Chinese woman, said:

Sometimes, my friends want to help me but my boss gets very upset, yelling, ‘When your hand is burst, I hope I won’t see you again.’ As a single mother with two children under the age of 1.5, I cannot afford to lose my job so I just ignore whatever he yells.

Ms Wong’s experience at work was just one of numerous examples offered by the women in similar working environments where limited help was available.

For women who could afford it, the strategy of paying for help was effective. For example, Ms Lou was relieved when she paid her granddaughter to help her clean the bathtub and do her laundry. The tasks most often paid for were cleaning, laundry, mowing the grass or yard work. However, insufficient financial resources was the most insurmountable barrier to this strategy for a lot of women. As Ms Ming, a 44-year-old Chinese woman who worked at a food company in Chinatown, remarked:

How could I pay for someone to help on my little income?

Another strategy often used by some women was to learn to perform tasks such as personal hygiene, cleaning, lifting heavy objects and cooking with their unaffected arms and hands. However, this was one of the most insurmountable barriers for women whose jobs required the use of both hands. The experience of Ms Kong, a 43-year-old Chinese data processor who had experienced lymphedema for eight years, was typical:

I try to use my other [unaffected] hand to type whenever nobody is nearby. But, most of the time somebody is watching. You don’t want to get fired during in this economic climate.

The women who worked at factories or pathological laboratories found it impossible to use this strategy since the nature of their work required the use of both hands. Moreover, those women found themselves helpless when it came to reducing the swelling and distressful symptoms since there was so little under their control. Ms Kong’s experience typified this:

Each day my swelling and pain become worse and the symptoms are so intense. I am caught in this dilemma: my work makes my lymphedema worse but I need my job.

Making daily care feasible

Upon completion of CDT, most of the women were told by their healthcare providers to perform a variety of tasks to manage their lymphedema on a daily basis, such as:

- Wearing compression sleeves and gloves
- Wearing heavy compression garments at night
- Using a pump when necessary
- Applying wraps or bandaging
- Performing self-massage and exercise
- Daily skin care
- Elevating the affected limb.

The women realised the importance of these tasks, yet even with clear instruction they were still overwhelmed by how much time it took. Most of them felt unprepared to begin their own lymphedema care at home. Ms Deb was a 56-year-old white woman. Her experience was typical:

I thought that my therapist gave me very clear instructions to follow when I finished my first round of therapy. But once I was on my own I found the reality so different. For example, for months and months it took me so long to get my sleeve on that I became frustrated. I called my therapist and she just said: ‘It should be better once you get used to it.’

One day, I was surfing online and found Easy-slide® range [Credenhill], which changed my life. I found it just takes a few minutes for me to put on my sleeve. I wish I had been told about this along with all the other instructions at the beginning.

Some women felt left alone to deal with lymphedema once the therapy was finished. Ms Lindsay, a 46-year-old African-American administrative aide, had the following experience:

I have been going to the same therapist for two sessions each year for four years because there are no other therapists for 60 miles around. Each time when we finish, she would say ‘All you need to do is to wear the sleeve day and night.’ But my swelling always gets worse and I have to go back to her as soon as my insurance permits. I am wondering if she is holding something from me.

When they were first diagnosed with lymphedema and started physical therapy, the women often tried to follow the daily compression instructions, e.g. wrapping, wearing compression sleeves, performing self-massage and elevation. However, as time went on they found it impossible to perform all of the required actions and had to prioritise those that were effective, required less energy and were easy to maintain. For example, the majority of the women decided that they would not apply wrapping on their affected arms as a daily maintenance procedure as it did not help to decrease the swelling significantly and was ‘time-consuming and exhausting’. Instead, they decided to continue with low maintenance activities such as wearing compression sleeves or performing self-massage, arm exercises and elevation.

As Ms Song, a 61-year-old Chinese woman, described:

I did wrapping for a while. It was not particularly effective for me but I did it because I was told to. Wrapping is time-consuming and awkward, so it’s
not just down to whether I can do it or not — I was actually depleted by wrapping. Putting on a sleeve on and elevating my arm is much easier and that’s what I do.

However, those without insurance, such as Ms Liu, a 53-year-old Chinese woman, found wrapping the cheapest way to maintain compression:

I know other ladies use the elastic sleeves but they are so expensive. I do not like wrapping but at least I do not need to replace them very often.

The fears of losing their jobs, stigma, embarrassment and discrimination were the most insurmountable barriers to compliance with daily compression. Ms Kong, for example, was so afraid of losing her job that she wore the compression glove during the night, on the way to work, during lunch or bathroom break:

I don’t want my boss to know that I am disabled by wearing the glove. But, once I start typing my arm becomes heavier and heavier and my hand becomes bigger and bigger. At the end of the day, I cannot even move my arm and curl my fingers. It is so distressing. All I can do during work is to hide the sleeve with a long-sleeve jacket, wear my glove during lunch break or, if the swelling becomes unbearable, go to bathroom and wear my glove for 10–15 minutes.

For women like Ms Kong, ‘wearing the compression garments as much as possible’ was feasible in sustaining their daily life by establishing and maintaining a routine. The women made the care of lymphoedema part of ‘getting ready for the day’. To maintain any established routine women tried to integrate it into their daily life by establishing and maintaining a routine. To make lymphoedema care feasible, the women tried to incorporate what they had to do around what they ‘wanted’ to do. For example, Ms Deanna, an 86-year-old white woman who had lived with lymphoedema for 23 years, learned to keep her underwear and her compression sleeve together every night:

I keep everything together so that I have easy access. I make it easy for myself in a way that I have more endurance.

Most of the women in the study had to wear compression gloves in addition to their compression sleeves. For them, it was a challenge to keep the gloves clean and dry because they could not wash their hands or wash dishes with their compression gloves on. They found that using rubber gloves over their compression gloves was an effective way to keep the compression gloves clean and dry. Some women used food processors to cut food to prevent injuries. Again, insufficient financial resources to pay for domestic helpers and a supply of rubber gloves remained the barriers to sustained daily lymphoedema care for many women.

Incorporating lymphoedema care into daily routine

To make lymphoedema care feasible, the women tried to integrate it into their daily life by establishing and maintaining a routine. The women made the care of their lymphoedema part of ‘getting ready for the day’. To maintain any established routine women such as Ms Lander, a 52-year-old white woman who had experienced lymphoedema for nine years, tried to foresee the changes in their lives and plan ahead:

In the morning, I take off my ReidSleeve® [Peninsula Medical] [a heavy compression sleeve for night wear] and put on my older Elvarex® sleeve [BSN Medical] [a light compression sleeve for day wear]. I drink my coffee then dress and go for a 30-minute walk. When I come back home, I have a shower and do my arm exercises. After that, I put on my newer Elvarex sleeve. I wear the newer sleeve all day until I get ready for bed.

While some women learned to ‘space out’ the household chores in order to cope, others tried to incorporate what they had to do around what they ‘wanted’ to do. For example, Ms Deanna, an 86-year-old white woman who had lived with lymphoedema for 23 years, learned to keep her underwear and her compression sleeve together every night:

I keep everything together so that I have easy access. I make it easy for myself in a way that I have more endurance.

At bedtime I take off my Elvarex sleeve and put the ReidSleeve back on and sleep in it. Then I repeat the process seven days a week without a break, especially when I am travelling or during my vacation.

Barriers that prevented the women from successfully establishing or sustaining a routine included lack of experience of establishing or maintaining a routine or schedule and working irregular hours. For example, Ms Meng, a 42-year-old Chinese nursing aide, usually worked an evening shift. However, on certain days of the week she would have to work a night shift:

My schedule has totally messed up my lymphoedema. I usually felt so tired whenever I came back from a night shift that I did not have the strength to do my massage and use the pump. So, I went to sleep without doing anything to my arm, I feel bad about it but what I can do.

Ms Holly, a 36-year-old African-American administrative manager, provided another example:

I’ve been having a hard time keeping to a schedule for my arm. I would try a week or so then I would mess up with the schedule. When I was a child, we lived in an unsafe neighbourhood. My mom always told us, Girls do not go to school and come back home using the same route. Do not let anybody guess your habits. So, I always changed my routes. When I grew up, I always change my routines and habits. I am not using this as an excuse, but maybe that’s why it has been so hard for me to keep my schedule.

Most of the married Chinese-American women, such as Ms Wong, usually waited until everyone was asleep at night before taking care of their lymphoedema.

You know, I am a mother and a wife so it seems odd for me to make a big show of my arm. I feel much more comfortable when
 everyone is sleeping and I can take some quiet time to deal with it. But sometime, it is so late and I am very tired. So, I would tell myself, ‘I’ll do it tomorrow’. Then, I ended up not doing anything.

**Discussion**

It should be noted that this study is limited in that it reflects the experience of thirty-four female breast cancer survivors with lymphoedema living in the US. The experiences of these 34 women may not represent all survivors’ experiences of managing lymphoedema. However, the findings of the study present an alternative perspective on compliance with lymphoedema management through the description of survivors’ experiences.

The women in the study listened to their healthcare providers’ instructions, however; they did not follow them exactly. Instead, the women tried to ‘make lymphoedema care feasible’. For example, the women were usually told to use daily compression. However, barriers such as insufficient time and financial resources, fatigue, fear of losing employment, stigma, embarrassment or discrimination often

### Table 4

<table>
<thead>
<tr>
<th>Intentions</th>
<th>Effective strategies</th>
<th>Barriers</th>
<th>Ineffective strategies</th>
</tr>
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<tbody>
<tr>
<td>Making conscious decisions about new-fangled limitations</td>
<td>Giving up</td>
<td>Lack of sufficient supporting system of family, friends, and coworkers</td>
<td>Ignoring</td>
</tr>
<tr>
<td></td>
<td>Letting go</td>
<td>Unsupportive working environment</td>
<td>Forgetting</td>
</tr>
<tr>
<td></td>
<td>Asking for help</td>
<td>Employers’ misunderstanding</td>
<td>Neglecting</td>
</tr>
<tr>
<td></td>
<td>Paying for help</td>
<td>Insufficient financial resources</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Using the unaffected limb</td>
<td>Occupations involving manual laborious work</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Impatience</td>
<td></td>
</tr>
<tr>
<td>Making daily care feasible</td>
<td>Wearing daytime compressive garments as much as possible</td>
<td>Lack of clear or detailed instructions</td>
<td>Trying to do all that you were told</td>
</tr>
<tr>
<td></td>
<td>Using Easy-slide® or other device to help putting on the compression sleeve</td>
<td>Insufficient time</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Wrapping the affected arm during nighttime</td>
<td>Insufficient financial resources</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Using rubber gloves to protect the compression gloves from getting dirty</td>
<td>Insufficient qualified therapists</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Performing exercise and massage if time and physical stamina allow</td>
<td>Fatigue</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Getting easy access to the things needed for lymphoedema care</td>
<td>Fear of losing job, stigma, embarrassment or discrimination</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Spacing out the household chores</td>
<td>Occupations involving manual laborious work</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Having someone help</td>
<td>Employers’ misunderstanding</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Wearing protective gloves for dish washing, cleaning, and gardening</td>
<td>Unsupportive working environment</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Using food processor to cut food</td>
<td>Lack of sufficient supporting system</td>
<td></td>
</tr>
<tr>
<td>Incorporating lymphoedema care into daily routine</td>
<td>Establishing and sustaining a daily routine</td>
<td>Lack of experience of organising or following a schedule</td>
<td>Following an irregular schedule</td>
</tr>
<tr>
<td></td>
<td>Forseeing the changes in life</td>
<td>Lack of experience of establishing or maintaining a routine</td>
<td></td>
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<tr>
<td></td>
<td>Readjusting to the established routine</td>
<td>Insufficient time</td>
<td></td>
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<tr>
<td></td>
<td></td>
<td>Irregular working schedules</td>
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<tr>
<td></td>
<td></td>
<td>Fatigue</td>
<td></td>
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<tr>
<td></td>
<td></td>
<td>Being a good wife and loving mother</td>
<td></td>
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</tbody>
</table>
Clinical RESEARCH/AUDIT

prevented them from following this instruction.

This could be regarded as non-compliant, however, as one of the respondents, Ms Wong, remarked: ‘This is not an issue about whether or not I have listened to my therapist, but how can I best make this work’.

Women who were not supported at work suffered from the constant fear of losing their jobs. Wearing compression garments as much as possible was their solution to the daily compression instruction. Some women were also instructed to perform daily self-massage, but fatigue or being tired were the most often reported barriers to maintaining this. In addition, lack of clear and detailed instructions regarding the nuances of daily living also prevented the women from following instructions to the letter. Such nuances included the most effective way to put on compression garments, how to keep compression gloves dry and clean, and avoiding heavy lifting and injuries.

For the women, managing lymphoedema was more complicated than simply complying with the treatment or prescribed daily regimen. Instead of passively following healthcare professionals’ instructions, the women actively and creatively structured their lives to ‘make lymphoedema care feasible’. The women did not consider selectively carrying out the prescribed daily regimen as non-compliance, but rather as a way of using strategies to ‘make daily care feasible’.

It is interesting that most of the married Chinese women used the strategy of waiting until every family member was asleep before taking care of their lymphoedema. This may reflect cultural influences as, in Chinese culture, women are expected to be a ‘good wife and loving mother’ whose role is to maintain harmony in the family in order to promote health (Simpson, 2005).

Conclusion

This study offers a new focus on lymphoedema management. It is important for researchers and clinicians to be aware that survivors do not consider compliance to treatment as part of their daily lymphoedema care. Instead of following exactly the instructions of healthcare providers, the women tried to determine what worked for them in order to make lymphoedema care fit in with their lifestyle.

Findings from the study provide an insightful alternative to the compliance approach to lymphoedema management. In practice and research, instead of assessing the degree of breast cancer survivors’ compliance with treatment, it may be more appropriate to assess how breast cancer survivors’ intend to structure their lives to manage lymphoedema.

Acknowledgement

The authors would like to thank the breast cancer survivors who shared their valuable experience in the study. This study was supported by a grant from National Institute of Nursing Research # F31 NR07851 and Alpha Iota Chapter, Sigma Theta Tau International, Honor Society of Nursing; a grant from NYU School of Education, and a grant from NYU Piess Center for Nursing Research.

References


Key points

» Breast cancer survivors do not consider compliance to treatment as part of their daily lymphoedema care.

» Breast cancer survivors structured their lives so that they were able to make lymphoedema care feasible.

» They did this by incorporating lymphoedema care into a daily routine.

» Major barriers to effective daily lymphoedema care include fatigue, insufficient financial resources and time.