

Living with lymphoedema after treatment for breast and gynaecological cancers in Singapore

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Key words

Lymphoedema, Experience, Singapore

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Declaration of interest: The study was funded by the Singapore Cancer Society. There is no conflict of interest as there is no further financial relationship with the funding body. The principal investigator and author has full control of all primary data and allows the journal to review the data if requested.

Breast cancer and gynaecological cancers are amongst the top ten most common cancer in women in Singapore (National Registry of Diseases Office, 2016). It is estimated that nearly one out of three cancers in women is breast cancer. As treatment improves, more women are surviving longer. However, they are left to overcome many treatment side-effects, such as lymphoedema.

Lymphoedema is a life-long condition caused by the gradual accumulation of lymph fluid within interstitial tissues (Maclellan and Greene, 2014). Women are at risk of developing it when cancer treatments such as lymph node resection surgery or radiotherapy remove or damage parts of the lymphatic system. The greater the damage, the higher the risk of developing lymphoedema (Shih et al, 2009; Todo et al, 2010).

Local statistics in Singapore are not readily available on the incidence of lymphoedema. Although international studies report an estimated incidence of 16.6–41.1% for breast cancer patients and 12.8–27.2% for gynaecological

Abstract

Background: Lymphoedema is a chronic swelling of the affected body part and can occur after surgical removal of lymph nodes and radiotherapy. It can have a debilitating impact on the lives of those affected. **Aim:** This study aimed to explore the experience of Singaporean women living and coping with lymphoedema. **Methods:** A semi-structured interview was conducted with women who developed lymphoedema after breast or gynaecological cancer treatment. Thematic analysis was done through three independent coders. **Results:** Four main categories were identified – perception towards lymphoedema, confronting challenges of managing lymphoedema, treatment motivators and suggested improvements. Patients with gynaecological cancer were more affected by adjustments in attire and footwear. Maintaining mobility motivated treatment adherence. Breast cancer participants preferred pre-operative education while those with gynaecological cancer felt information should be regulated. **Conclusion:** There is a longing for normalcy as women adjusted their lives to manage with lymphoedema. More can be done to help support them. Further research is needed to explore alternative treatment options to enhance their lives.

patients, studies cited problems with high heterogeneity across the studies and non-standardised criteria for reporting as key limitations (Füller et al, 2008; Tada et al, 2009; DiSipio et al, 2013; Hopp et al, 2016; Pereira et al, 2017).

Patients with lymphoedema often present with swelling, tightness, heaviness, pain and reduced arm movement, worsening with the progression of the condition (Lawenda et al, 2009; Fu et al, 2015). Treatment usually comprises a combination of skin care, exercise, manual lymph drainage and compression therapy.

However, despite its perceived effectiveness in relieving lymphoedema, compression therapy is met with non-compliance due to its discomfort and the increased financial burden arising from the cost of physiotherapy treatment and supplies (Ryan et al, 2003; Fu, 2005; Boyages et al, 2017). Its discomfort is especially significant in hot and humid countries where the use of multi-layered bandaging is highly uncomfortable, rendering it least popular amongst patients with lymphoedema.

While these previous studies reported common themes such as a sense of lethargy and disability, aesthetic concerns arising from the condition and treatment, and the impact these garments and the signs and symptoms of lymphoedema have on their daily activities and quality of life, there has not been any report on how the experience of living with lymphoedema may differ in Singapore (Voogd et al 2003; Fu, 2008; Mak et al, 2009).

This study aims to explore the experience of Singaporean women coping and living with lymphoedema in the following key areas:

1. Their perceptions of lymphoedema.
2. How they are managing their lymphoedema.
3. What makes them take care of their lymphoedema.

Methods

Participants and recruitment procedures

After institutional review board approval, purposive sampling was carried out to recruit up to 20 participants or until no new themes emerged from consecutive

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interviews. Recruitment brochures were made available at clinics. Electronic letters were sent to physicians to inform them about the study. Eligible women attending the lymphoedema clinic at the physiotherapy department at KK Women's and Children's Hospital were also invited to the study through a letter of invitation. Those who responded and were eligible gave informed written consent to participate in the study ($n=12$; study participants: S1–S12).

The women included were Singaporeans above the age of 21 years who completed surgery and/or radiotherapy treatment for breast cancer or gynaecological cancer at least 3 months previously, were clinically diagnosed with lymphoedema at least 1 month prior to study recruitment and resided in Singapore since the onset of lymphoedema (Table 1). For the purpose of informed consent and the interview, they had to be English speaking.

The median age was 61.25 years (range 51–73). Four had breast cancer and eight

had gynaecological cancer. The time of onset of lymphoedema from cancer surgery varied from less than a year to 18 years. The duration of living with lymphoedema ranged from 9 months to 9 years.

Research design

The study took on a phenomenological approach to explore participants' experience through use of audio taped face-to-face interviews conducted in a private room at the hospital's physiotherapy department. The semi-structured interviews took approximately 23–90 minutes to complete, using guiding questions about patients' perceptions of lymphoedema; experience with treatment methods; and challenges faced and their needs (Appendix 1).

Findings depended on how participants willingly shared their experiences and questions were kept open-ended, with preconceived perceptions of the investigator set aside.

The interviews were transcribed verbatim by an independent transcriber. The principal investigator listened and checked the transcripts before they were forwarded to another two coders to label and categorise the codes independently. Any discrepancies in categories were discussed in depth until consensus was obtained and validated. Participants also returned for a second interview to verify identified codes and themes.

Results

The analysis resulted in four broad categories (Table 2). There were some differences between the perceptions of patients with gynaecological cancer and breast cancer.

Category 1: Perception towards lymphoedema

Sense of resignation

All participants felt resigned to spending the rest of their lives living with lymphoedema. They expressed having no choice and requiring to manage it through the various treatment methods. Anger and sadness upon the initial diagnosis was evident among them as they tried to come to terms with their knowledge about the chronicity of lymphoedema.

"It gets a bit disheartening to think about the fact that this is one issue that I cannot outrun and something that I have to live with." (S1)

"Damage done already, la, so I get along with it, la." (S5)

Self-comforting strategies

Many comforted themselves that it could have been worse. The fact that lymphoedema was not painful helped make it more manageable.

Breast cancer patients felt that having lymphoedema in the arm seemed better than having a swollen leg.

"I think I wouldn't want to have it on the leg. I think I will prefer the arm." (S2)

"If the situation remains as it is now, it is something that I could live with. But if I were to suffer more pain and after that it doesn't go away, then it's something that I'm not prepared to live with." (S11).

Category 2: Confronting challenges of managing lymphoedema

Attire and footwear adjustments

The struggle of finding the appropriate attire and footwear to accommodate the swollen limb and its asymmetrical size affected those with swollen legs more. Although almost all participants expressed discontent, those with gynaecological cancer expressed greater angst in not being able to don their favourite clothes or heeled shoes.

Both groups felt the need to hide the affected limb in order to escape repeated questioning from others. This loss of privacy exposed their cancer diagnosis from others, impacting on their self-image and self-esteem.

"It actually looks very awful when you are wearing form fitting pants... I look very stumpy. I hate that, I don't like it." (S1)

"I haven't been wearing skirt or shorts or anything like that. Always long pants to hide the legs." (S10)

"People will always ask out of concern whether oh, whether you hurt yourself or whether you... it is very difficult to explain to people." (S11)

Lifestyle modifications

Time needs to be set aside to ensure compression garments or bandages are put on prior to moving around or leaving home for both groups of participants. This

Table 1. Characteristics of study participants.

| Characteristics | $n=12$ |
|---|---------------|
| Age, years (range) | 61.25 (51–73) |
| Ethnicity | |
| Chinese | 9 |
| Malay | 2 |
| Indian | 0 |
| Eurasian | 1 |
| Type of cancer | |
| Breast | 4 |
| Gynaecological | 8 |
| Completed chemotherapy | 8 |
| Completed radiotherapy | 5 |
| Location of lymphoedema | |
| Arm | |
| Left | 2 |
| Right | 2 |
| Leg | |
| Left | 5 |
| Right | 2 |
| Bilateral | 1 |
| Onset of lymphoedema, years after surgery (range) | 5.25 (1–18) |
| Duration of lymphoedema, years (range) | 4.13 (0.75–9) |

activity became “that extra thing in life” (S3). There is a change in priorities as they had to reschedule appointments to avoid going out wearing visible bandages.

“[I] give myself more time to prepare before I go out... I think to remember to ask myself before I do anything if I can or can't do it... I must remember I need to rest.” (S12)

Social and work appointments were sacrificed to accommodate time needed for therapy as well as to avoid situations when infection was likely to be triggered. Daily activities like mopping the floor or cleaning the toilet become difficult or impossible as these women grapple with the dilemma of avoiding prolonged standing without compression and needing to complete these chores as part of their role as homemakers.

“[I] cannot carry my grandchildren, I cannot play with them, cannot run with them.” (S6)

Treatment discomfort hinders compliance

Most participants reported their struggles with the discomfort while complying with treatment. Treatment such as multi-layer bandaging also restricted their movements such as being able to type on a keyboard at work or step up to board a bus, depending on the limb affected.

Compression garments were thick, tight and difficult to don and often leave skin irritations and heat rash with prolonged use.

“It tends to cause the flesh here to... cuts into the flesh. So it's a bit painful.” (S2)

“Because of the weather in Singapore. So sometimes I just wore it, sometime I didn't wear it.” (S10)

Treatment is time consuming

Participants found treatment time consuming. They needed to take time off work and to travel for frequent therapy sessions. Garments were tight and difficult to don and required participants to wake up earlier or set aside more time to prepare prior to leaving home. Bandaging was time consuming and a burden when family members helped with treatment.

“Now because of leg, my leg I have later appointment. A lot of things like dressing up, you have to consider.” (S5)

Cost of treatment

Attending therapy sessions and obtaining compression garments posed a financial burden, especially those without insurance coverage or government subsidies.

“[A] very expensive condition... whether there can be better provision of healthcare subsidy for those who have the condition but who probably do not have the means to pay even for subsidised treatment.” (S11)

Category 3: Treatment motivators

Fear of worsening ensures treatment adherence

Compliance to treatment was motivated by the fear that it would worsen should they not comply. This supported the findings of resignation to complying with treatment. All patients were afraid that their condition would worsen or the effects of treatment effect would be undone should they decide to not adhere to treatment.

“All through the problem of wearing everyday and then just one day of not wearing it, the problem is... just straight away come back staring at my face.” (S1)

“Of course you have to continue, if not when you swell that time you can feel the uncomfortableness.” (S3)

The need to maintain normalcy

Compliance was also driven strongly by the need to maintain independence and quality of life. Maintaining mobility is one

of the key motivators among participants with gynaecological cancer, so they could continue activities they enjoy, such as sports, and resume their roles among family and friends, such as being able to carry a grandchild.

“I want to move, I want to travel. I want to move around 'cos... I'm still young.” (S5)

Category 4: Suggested improvements **Support group will be helpful**

Most participants initiated the idea of having a support group for women to share their experience and to provide support for each other. They commented on how it was not common to meet others with a similar condition and how it can help them emotionally.

“I've never seen another person... having the same bandage as me. But I never ever see one patient doing the same bandage as me outside... is it only me?” (S10)

“It's the various sharing, sharing the possibility of developing another condition, the symptom is one thing. Also assuring that... there is help, you know.” (S9)

Early education is important

Most participants felt that early knowledge was crucial in helping them prevent or manage their condition better. In particular, all breast cancer participants preferred pre-operative education to be given, but some with gynaecological cancer felt that this

Table 2. Categories and subcategories of patients' perceptions of lymphoedema, experience with treatment methods, challenges faced and their needs.

| Category | Perceptions of gynaecological cancer patients | Perceptions of breast cancer patients |
|--|--|---|
| Perception towards lymphoedema | <ul style="list-style-type: none"> Resignation Self-comforting strategies | <ul style="list-style-type: none"> Resignation Self-comforting strategies |
| Confronting challenges of managing lymphoedema | <ul style="list-style-type: none"> Attire and footwear adjustments Lifestyle adjustments Treatment discomfort hinders compliance Treatment is time consuming | <ul style="list-style-type: none"> Lifestyle adjustments Treatment discomfort hinders compliance Treatment is time consuming |
| Treatment motivators | <ul style="list-style-type: none"> Fear of worsening Need to maintain normalcy especially mobility | <ul style="list-style-type: none"> Fear of worsening Need to maintain normalcy |
| Suggested improvements | <ul style="list-style-type: none"> Support group will be helpful | <ul style="list-style-type: none"> Preoperative education preferred |

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information should be regulated so as not to overwhelm patients.

"I think given as early as the first follow-up, should alert the patient... pre-empt the patient." (S9)

Discussion

Research exploring the experience of women living with lymphoedema in Singapore is absent. This study had its own limitations as its study sample was not representative of the demographic distribution of multicultural and multinational Singapore.

Although this study attempted to reflect the experience of patients with lymphoedema after treatment for breast and gynaecological cancer, the results cannot be generalised to all Singaporeans with lymphoedema. Nonetheless it is the first to look at how these women manage and cope with lymphoedema in Singapore.

There were similarities in how those with lymphoedema had to adjust to prevent its exacerbation and to

accommodate its care. Many had to make sacrifices and change their hobbies and daily activities, as has been found elsewhere (Fu, 2010; Jeffs et al, 2016).

There seemed to be a loss of role and functioning among family, friends and colleagues as Singaporean women with lymphoedema felt they could no longer carry out their duties as they did in their pre-lymphoedema days. There is a yearning to regain normalcy. Those with swollen legs were concerned about how their mobility might be hindered from the condition and its treatment.

There was also a strong sense of loss of privacy. Almost all participants felt that the enlarged limb and their compression garments made them more self-conscious in public. They were subjected to repeated questioning by their peers and the public. There seemed to be a loss of face among Asians, as many preferred not to disclose their diagnosis to others.

Lymphoedema can be perceived as a disability, considering the impairments in the lymphatic system lead to body and structural changes and its sequelae of

limitations in activity and participation.

Viehoff et al attempted to explore and develop core sets of the International Classification of Functioning, Disability and Health for lymphoedema (Viehoff et al, 2015). Core sets such as body image, daily routine, hosiery and self-management are much in sync with the findings of this study. However, it is important to note that these are largely based on countries representing North America, Europe and the Western Pacific and that the patient types are not exclusive to breast and gynaecological cancer.

Societal and financial support is lacking for lymphoedema patients in Singapore. Patients have to pay for healthcare and lymphoedema treatment and its necessary adjuncts are not commonly covered by private insurance or government subsidies. Support from employers is needed, not only to take time off work for treatment, but also to accommodate modifications to the nature of work – and these are not always provided.

There is a growing need to recognise the debilitating effects of lymphoedema

Appendix 1. Semi Structured Interview Questions Version 1 (2 Feb 2015)

(a) Perceptions of lymphoedema

1. What do you know about lymphoedema?

- What were you told about lymphoedema?
- What do you understand about lymphoedema?

2. How did you and from whom did you find out that you have lymphoedema?

- How was the news shared to you?
- Did you know about lymphoedema beforehand?
- How would you prefer or wish this news to be shared to you?

3. How did you feel?

- How do you feel upon your diagnosis of lymphoedema?
- How has lymphoedema affected you and your life?
 - Has lymphoedema also affected people around you? If so, how?
 - How have others responded to you having lymphoedema?
 - How do you feel?

(b) Management of lymphoedema

1. What treatment did you have for lymphoedema?

- What were the options offered to you?
- How did you feel about your treatment?
- If you did not receive any treatment, why not?

2. How did you comply?

- How often did you receive treatment?
- How did you manage at home?

3. How was your experience with your treatment?

- What were the challenges you faced with your treatment?
- What did you do to help yourself manage with the treatment?

(c) Self-management

1. If you received treatment, what motivates you to seek and receive treatment for lymphoedema?

2. If not, how have you been managing on your own?

3. What are the challenges you face with managing lymphoedema on your own?

- How have you overcome these challenges?
- What are some of the positive experiences, if any, that you have gained from your condition and its treatment?

4. What resources or help do you think will help you manage your lymphoedema better?

- What information would you prefer to be shared with you to help you manage better?
- When do you prefer these resources to be made available or known to you?

and for stakeholders and policy makers to consider how their needs can be met.

In light of this research, it is clear more needs to be done to examine the perception of healthcare providers and policy makers towards lymphoedema, as well as explore various innovative treatment regimens or options to better cater to those living in Singapore.

Conclusion

This study highlights the adjustments to various aspects of daily living that patients with lymphoedema have had to make in order to cope with the behaviour of the condition and its treatment. Whether they are homemakers or working professionals, there is a sense of loss of normalcy in their lives and the need to adhere to treatment to prevent its exacerbation. Greater awareness and more research on the impact of lymphoedema can possibly help healthcare providers and policy makers consider how better to render support to these patients.

Acknowledgements

This study was supported by the Singapore Cancer Society. I thank my colleagues from KK Women's & Children's Hospital, June Eng Feng Cai and Barbara Wee Chun Sian, for

assisting in the review of transcriptions and coding for the patient interviews, as well as Catherine Chua Bee Hong for supporting the study.

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