

# Psychosocial Impact of Lymphoedema After Breast Surgery

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**Abstract** Lymphoedema (LE) secondary to cancer is the side effect of cancer treatments and may appear on breast cancer (BC) survivors' upper limb post-surgery. Several symptoms other than swelling have been reported. LE onset adversely affects the emotional and psychological state of BC survivors, leading to anxiety, depression, body image issues and altered psychological quality of life (QoL). In sufficient informational support, physical limitations, compression garments, LE symptoms and age are associated with the emotional and psychological sequelae. Social impact of LE, such as social confidence, job security and sexuality and relationship with partners, has also been reported. The visibility of LE, its association with BC and compression garments are associated with LE-related social sequelae. Several studies aiming at both LE prevention and QoL improvement have been conducted. However, their efficacy, especially in minimising psychosocial sequelae among BC survivors with LE, remains to be confirmed.

**Keywords** Body image · Depression · Intervention · Intimate relationships · Lymphoedema · Social confidence · Breast cancer · Review

## Introduction

Lymphoedema (LE) secondary to cancer is a chronic condition that significantly impacts the quality of life (QoL) of breast cancer (BC) survivors globally [1–4]. Cancer treatment-related risk factors have been intensively examined with the goal of minimising the negative impact of LE; axillary lymph node dissection [5••] and adjuvant radiotherapy have been consistently reported as LE risk factors among BC survivors [6, 7]. These treatment approaches may lead to altered lymphatic flow, precipitating the accumulation of the protein-rich fluid and consequently leading to swelling on the operated side of the upper limb. The incidence of LE following axillary lymph node dissection among BC survivors is approximately 20 % [5••, 8]. Although a sentinel node biopsy is associated with a relatively lower risk of LE [9], approximately 6 % of BC survivors who undergo this surgical method still develop LE post-surgery [5••].

The onset of LE varies among individuals; some BC survivors develop LE 5 years after treatment [1, 10••], whereas others never develop LE after the treatment in the rest of their lives. LE-associated complications include inflammation and infection caused by tissue damage of the affected skin; thus, protection of the affected limb during everyday functions is particularly important. Thereby, there is an increasing interest in identifying lifestyle-related LE risk factors including weight control as well as risk reduction measures to prevent and/or treat infections, trauma, sunburn,

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heavy lifting, overuse of arms, venipuncture and sauna use [11, 12••] to minimise the negative psychosocial consequences during BC survivorship.

## The Lymphatic System

The lymphatic system, which consists of lymphatic vessels and lymph nodes, covers the entire human body. Lymph nodes, small glandular structures, are located in the armpits, neck, chest, legs, abdomen and pelvis and are connected by lymph vessels that carry lymph that is the lymphatic fluid enriched with lymphocytes. The lymphatic system functions to prevent infections and to filter waste products from blood. If the filter function does not work properly, protein and water accumulates in the extracellular space between the lymph vessels and veins and LE develops. However, impairment of the lymphatic system does not always spontaneously trigger oedema as compensatory mechanisms attempt to find alternative lymph vessels to normalise lymphatic function [13]. Therefore, the onset of LE is difficult to predict and underlies the delays in preventative care.

## Symptoms of LE

Despite oedema literally means swelling, it is not the only symptom of LE as shown by several studies. As an example, a survey study in the UK ( $n=823$ ) has revealed that 50 % of patients with LE reported pain or discomfort [14], although pain was not considered as an LE symptom in clinical settings. Similarly, another study in the UK ( $n=677$ ) showed that 45 % of BC survivors suffered from pain, which was rarely reported by BC patients without swollen limbs [15]. Another study in the UK conducted on BC survivors with LE ( $n=36$ ) revealed that 43 % of participants experienced numbness and that 37 % reported stiffness [16]. A recent study in Brazil that analysed BC survivors who had undergone surgery within the previous 5 years showed that poor joint mobility was significantly associated with the presence of LE [10••]. Because these symptoms tend to appear under the armpits, on the upper arm, forearm, shoulder or chest wall [17], physical limitations [18] and poor physical performance in daily activities [19] are observed frequently among BC survivors with LE.

## Diagnosis and Therapeutic Management of LE

To identify whether a BC survivor has developed LE, several measurement methods, including the water displacement method, circumferential limb measurement, optoelectric perometry and bioimpedance, have been suggested; however, circumferential limb measurement is the most commonly used

approach in clinical practice. A difference of more than 2 cm between the operated and unoperated arms is a clinical sign for both LE diagnosis and treatment [20]. If BC patients have any of the abovementioned symptoms, immediate treatment is typically required to prevent its evolution to a more severe condition. To exert pressure on the affected side and aid in the return of the excess fluid in the tissue back into the lymph vessels, several therapeutic approaches, such as skin care, exercises, compressions sleeves, multilayer bandaging, manual lymphatic drainage (MLD) and simple lymphatic drainage (SLD), have been suggested. Therapists usually utilise a combination of these methods for combined decongestive lymphatic therapy (CDLT), tailored to each patient depending on the upper limb condition [20].

## Psychosocial Sequelae of LE

### Psychological Sequelae

As revealed by systematic reviews [21,22], majority of studies reported that BC survivors with LE are more likely to report poor emotional and psychological wellbeing than those without LE. The impact of LE is reflected in the presence of anxiety, depression, poor body image and poor psychological QoL in these patients [21–23]. Several studies have identified factors associated with emotional and psychological sequelae, for example, insufficient or unsatisfactory medical information on LE, physical limitations, use of compression garments, pain and younger age [4, 14, 24, 25, 26, 27••].

Results showed that in cases where information on treatment-related risks and LE management were not sufficiently provided before discharge, BC survivors were more likely to develop anxiety or fear regarding upper limb problems when these developed and were more likely to feel frustrated with the medical consultation [27••]. After LE onset, even in cases where the patients sought help, LE diagnosis and its appropriate care was merely provided [27••]. These factors may lead to the development of psychological distress in BC survivors [18].

Because of the physical limitations and use of compression garments, BC survivors with LE tend to perceive themselves as disabled [28], less feminine and less attractive [25]; they often struggle with unanticipated body image changes if information on LE risks are not adequately provided. A study in Australia showed that BC survivors with LE below 50 years of age were more likely to report needs for informational support for their body image [27••]. A current study in the USA illustrating the underlying mechanism between LE symptoms, body image and emotional wellbeing showed that pain increased the degree of dissatisfaction with body image and consequently increased depressive symptoms among BC survivors with LE [29]. However, because a variable on

information provision about LE was not included in the study, it was unclear how informational support was associated with these relationships; perceived insufficiency of information provided was suggested to affect the degree of acceptance of LE [18]. The effect of informational support on LE symptoms, perceived body image and emotional wellbeing should be investigated in future research.

### Social Sequelae

Although few studies have investigated the social sequelae of LE, compared with its psychological sequelae, systematic reviews [21, 22] have shown that BC survivors with LE are more likely to report poor social functioning and social wellbeing than those without LE; particularly impacted areas include social confidence, job security, sexuality and relationship with partners [21, 22]. Studies have shown that because LE is visible and is one of the side effects of cancer treatment, social embarrassment occurs between BC survivors and others. Some BC survivors wish to withhold their diagnosis and thus experience anxiety when others inquire about the reason for the swollen limb. Qualitative studies described strategies that BC survivors often used when they were asked about their LE-related physical limitations. For example, a study in Japan showed that patients selectively disclosed LE to their friends to avoid discomfort during interactions with them and/or to maintain perceived normality [30]. Similar strategies have been reported by a study in Sweden, which showed that working women described how they learned that it was better to provide misinformation about their upper limb problems and BC when asked [31]. Because perceived normality is important to maintain the self [32], some BC survivors are not willing to disclose LE to others even in cases where they seek help for lifting heavy objects. Although issues of employment among BC survivors with LE have not been fully investigated yet, a qualitative study in the USA showed that seeking help for lifting heavy objects appeared to threaten job security in certain work environments [33].

BC treatment itself affects the sexuality of survivors [34], but the limited research conducted for elucidating the impact of lymphoedema and its treatment on women's sexuality. Recent studies have revealed that both the symptoms and treatment of LE adversely affect patients' sexuality and relationship with their partners. For example, a mixed-method study in the USA ( $n=243$ ) has revealed that approximately 57 % of BC survivors with LE complained that LE symptoms affected their sexual activities, and the interview data showed that the use of compression garments adversely affected both sexual desire and sexual activities [35••]. In addition, studies in North America showed that the use of compression garments led to changes in intimate relationship between partners and BC survivors and led to less leisure time together [36–38].

### Intervention to Minimise the Psychosocial Sequelae of LE

As shown by previous research [29], LE symptoms significantly affect the psychosocial wellbeing of BC survivors; thus, interventions primarily aim to prevent the onset of LE with secondary aim to improve their QoL. Although several interventions have been evaluated, there are no definitively effective interventions that can minimise psychosocial sequelae specifically among BC survivors with LE. For example, a meta-analysis reported that weight training interventions were effective in reducing the incidence of severe LE, improving limb strength and the physical domain of QoL scores; however, the psychosocial domain of QoL scores did not improve [39, 40]. Another study in the USA demonstrated significant effects of weight training intervention on appearance and sexuality scores; however, these effects were not significantly different between BC survivors with LE and those without LE [41]. Several studies investigated the efficacy of yoga on the reduction of arm volume and improvement of psychosocial QoL. The results were inconclusive because the sample size of these studies was small and because the studies were preliminary [42, 43].

To facilitate the restoration of lymphatic functions after BC treatments, education on complementary therapies, including skin care, risk reduction measures and self-massage or manual lymph drainage massage, have been recommended [20]. A recent meta-analysis [44, 45] has reported that massage is not effective for either limb volume reduction or QoL improvement among BC survivors. These findings may be because several studies in the meta-analysis in which long-term massage effects beyond 6 months on LE prevention and QoL improvement were not assessed [44]. Therefore, research focusing on the long-term effects of complementary therapies should be conducted in future.

### Conclusions

BC-related LE develops in the setting of impaired lymphatic system by BC treatments and life style-related factors. However, even in cases where BC treatment impairs the lymphatic system, LE will not necessarily develop. Furthermore, the timing of its onset is not readily predictable. Studies have consistently shown that BC survivors with LE complain about several LE symptoms other than swelling. These symptoms significantly affect not only the physical aspects but also the psychosocial status of BC survivors. Emotional and psychological sequelae include anxiety, depression, negative body image and poor psychological QoL. Communication between health care professionals and BC survivors, physical limitations and compression garments, younger age and pain are associated with these psychological sequelae. Social sequelae

include social embarrassment, employment issues and relationship with partners. Visible swollen limbs, the cause of LE, physical limitations and compression garments are associated with these social sequelae. Although interventions including weight training and yoga have been evaluated, their efficacy has not been conclusively shown to improve the psychosocial domains of QoL. In addition, the efficacy of complementary methods, such as massage, has not been proven to be effective in either arm volume reduction or psychosocial wellbeing. Further studies should assess the long-term effects of complementary methods. In addition, new modalities, such as multidisciplinary approaches addressing the psychosocial sequelae, should be developed for improved satisfaction of BC survivors.

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#### Compliance with Ethical Standards

**Conflict of Interest** Miyako Tsuchiya and Miyako Takahashi declare that they have no conflict of interest.

**Human and Animal Rights and Informed Consent** This article does not contain any studies with human or animal subjects performed by any of the authors.

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