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# Financial cost of lymphedema borne by women with breast cancer

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# Financial cost of lymphedema borne by women with breast cancer

## **Abstract**

Psycho-Oncology Published by John Wiley & Sons Ltd. Objective: Our study examines the financial cost of lymphedema following a diagnosis of breast cancer and addresses a significant knowledge gap regarding the additional impact of lymphedema on breast cancer survivors. Methods: An online national survey was conducted with 361 women who had either breast cancer without lymphedema (BC) (group 1, n = 209) or breast cancer with lymphedema (BC+LE) (group 2, n = 152). Participant recruitment was supported by the Breast Cancer Network Australia and the Australasian Lymphology Association. Results: Both breast cancer and lymphedema result in significant out-of-pocket financial costs borne by women. Of patients with BC+LE, 80% indicated that their breast cancer diagnosis had affected them financially compared with 67% in the BC group ( $P < .020$ ). For patients with lymphedema, over half (56%) indicated that this specific additional diagnosis to their breast cancer affected them financially and that costs increased with lymphedema severity. The cost of compression garments formed a large proportion of these costs (40.1%). The average number of attendances to a therapist each year was 5.8 (range, 0-45). Twenty-five patients (16.4%) had an episode of cellulitis in the past year. The incidence of cellulitis was 7.7% in 91 patients with subclinical or mild lymphedema compared with 29.5% of 61 patients with more extensive lymphedema ( $P < .001$ ). The average out-of-pocket financial cost of lymphedema care borne by women was A\$977 per annum, ranging from A\$207 for subclinical lymphedema to over A\$1400 for moderate or severe lymphedema. Conclusions: This study identifies an additional detrimental effect of lymphedema on women in terms of financial costs.

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## PAPER

# Financial cost of lymphedema borne by women with breast cancer

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## Abstract

**Objective** Our study examines the financial cost of lymphedema following a diagnosis of breast cancer and addresses a significant knowledge gap regarding the additional impact of lymphedema on breast cancer survivors.

**Methods** An online national survey was conducted with 361 women who had either breast cancer without lymphedema (BC) (group 1, n = 209) or breast cancer with lymphedema (BC+LE) (group 2, n = 152). Participant recruitment was supported by the Breast Cancer Network Australia and the Australasian Lymphology Association.

**Results** Both breast cancer and lymphedema result in significant out-of-pocket financial costs borne by women. Of patients with BC+LE, 80% indicated that their breast cancer diagnosis had affected them financially compared with 67% in the BC group ( $P < .020$ ). For patients with lymphedema, over half (56%) indicated that this specific additional diagnosis to their breast cancer affected them financially and that costs increased with lymphedema severity. The cost of compression garments formed a large proportion of these costs (40.1%). The average number of attendances to a therapist each year was 5.8 (range, 0–45). Twenty-five patients (16.4%) had an episode of cellulitis in the past year. The incidence of cellulitis was 7.7% in 91 patients with subclinical or mild lymphedema compared with 29.5% of 61 patients with more extensive lymphedema ( $P < .001$ ). The average out-of-pocket financial cost of lymphedema care borne by women was A\$977 per annum, ranging from A\$207 for subclinical lymphedema to over A\$1400 for moderate or severe lymphedema.

**Conclusions** This study identifies an additional detrimental effect of lymphedema on women in terms of financial costs.

## KEYWORDS

cancer, cellulitis, cost, lymphedema, oncology

## 1 | INTRODUCTION

As the number of breast cancer survivors increases with more effective treatments, the number of patients with long-term side effects including lymphedema also increases.<sup>1</sup> Surgery and/or radiation therapy disrupts the lymphatics and thus increases the risk of fluid accumulation.<sup>2,3</sup> The incidence of breast cancer-related lymphedema

(BCRL) ranges from 5% with conservative treatment alone (lumpectomy or wide local excision and sentinel node biopsy) to greater than 50% in cases with axillary node dissections and nodal irradiation.<sup>4–8</sup> Patients who are obese or develop postoperative seroma or infection are at added risk.<sup>9</sup>

Lymphedema not only causes pain and limits a patient's activities of daily living but also directly impacts the financial costs to the individual

through copayments for increased medical and therapist consultations and the direct costs of compression garments and other treatment-related medical expenses.<sup>10</sup> Lymphedema also increases the impact on employment and career, which can also affect finances. For example, patients may need to have more time off work or transition from full-time to part-time employment to increase the time available to manage the complex care required, particularly with advanced lymphedema.<sup>11</sup>

However, research into lymphedema is still limited, regarding not only diagnosis and treatment but also the impact on a patient's quality of life and costs to the economy. In a recent systematic analysis by the International Lymphoedema Framework, Stout<sup>12,13</sup> argued that implementation of care models for lymphedema faced several barriers, including the lack of population-based prevalence studies, and specifically highlighted the lack of information on the economic burden of the disease as data regarding lymphedema cost management and related complications are limited.

Post-treatment survivors of cancer face practical concerns relating to financial costs. Patients with BCRL have higher treatment costs: for example, compression therapy, the most crucial element in the management of chronic lymphedema, involves wearing compression garments on the affected limb. While ready-to-wear compression garments cost A\$130 to \$250, customized garments deliver significantly better results but cost approximately A\$300 to A\$500. Patients require a minimum of 2 garments at a time to allow for washing, and these require replacement every 6 months. In many countries, including Australia, there is little government support for lymphedema, and private health insurance reimbursement depends on the patient's level of cover. In addition, patients with lymphedema are more likely to spend more time in hospital owing to lymphangitis or cellulitis, known to contribute to a more advanced condition and compound medical costs.<sup>14</sup>

Scholars are beginning to examine these financial costs. Shih et al<sup>15</sup> found that the 2-year mean costs for women with BCRL were a significant US\$23 167 higher than for patients with breast cancer without lymphedema (BC). In a recent study of 56 075 women, 2.3% had at least 1 hospital admission for complicated lymphedema within 2 years of breast cancer surgery.<sup>16</sup> Along with significantly more inpatient admissions, patients with BCRL incurred nearly 7-fold greater health care charges compared with those patients without lymphedema. This high rate of hospitalization resulted in substantially higher health care charges (US\$58 088 vs US\$31 819 per patient,  $P < .001$ ) over the 2-year period after surgery. However, studies of this type are constrained because of the use of administrative claims data, which are likely to underestimate true incidence rates and costs.<sup>13</sup> With this in mind, we undertook a mixed-method qualitative and cross-sectional quantitative study to begin to further understand the impact of lymphedema over and above breast cancer in this important dimension.

## 2 | METHOD

### 2.1 | Setting

A survey of breast cancer survivors with and without lymphedema was undertaken Australia-wide. Participants were asked to complete an

electronic survey examining the impact of lymphedema over and above breast cancer on their employment, social life, self-esteem, body image, and finances. This report specifically addresses the impact of lymphedema over and above breast cancer on the financial costs borne by women.

### 2.2 | Study population

Owing to limited knowledge about the socioeconomic impact of lymphedema, an exploratory qualitative methods approach was used that entailed interviews with 30 individuals—10 with primary lymphedema and 20 with secondary lymphedema. During the second phase, reported here, we used survey methodology to collect extensive data on the impact that living with secondary lymphedema has on breast cancer survivors. The survey instrument is available on request. A complexity addressed in the study was how to differentiate the impact of a diagnosis of lymphedema over and above a diagnosis of breast cancer. The survey instrument therefore had 2 sections looking at the impact of lymphedema first (if present) and then breast cancer for all patients.

Individuals eligible for study participation were as follows: female; older than 18 years; previously diagnosed with primary stage I, II, or III breast cancer; had completed treatment at least 1 year prior to recruitment; and fluent in English. Individuals who fulfilled these criteria alone became the control group. In addition, we targeted individuals who fulfilled all the criteria above and also had a confirmed diagnosis of lymphedema, by either a doctor or lymphedema therapist, including patients with subclinical lymphedema diagnosed through bioimpedance spectroscopy (L-Dex) alone; had sought therapist advice; and/or were wearing compression garments. Participants completed the study questionnaire online.

Women previously diagnosed with breast cancer were approached for study participation through an Australian community-based breast cancer consumer organization, the Breast Cancer Network Australia (BCNA). An e-mail invitation was sent by a contact person within the BCNA to members who had previously agreed to receive notifications about research studies. Patients with lymphedema were also asked to consider the study through the Australasian Lymphology Association (ALA) and through notices in the clinics of the authors (J.B., L.K., and H.M.). Contact was made with an estimated 1600 patients with BC and 700 with breast cancer with lymphedema (BC+LE), and it was the responsibility of the women who received the e-mail to determine their eligibility for the study. A total of 361 women agreed to participate. Following online consent, participants anonymously completed the 30-minute questionnaire. The survey contained questions relating to the impact lymphedema had on family, social/leisure activities, and employment, as well as self-esteem and identity. The conduct of this research was approved by the Macquarie University Human Research Ethics Committee.

### 2.3 | Definitions

We asked a screening question so as to classify our respondents' lymphedema stage (Sheila Ridner, personal communication). We asked

participants to reflect on their condition for the last month and report on its severity by choosing one of the following categories.

- No problem: no noticeable swelling. We later termed this category as subclinical lymphedema detected by a therapist or clinician using girth measures or bioimpedance spectroscopy (L-Dex®).
- Mild lymphedema: soft swelling that is not obvious to others and comes and goes.
- Moderate lymphedema: swelling with occasional hardness in some areas that is obvious to others and is always present.
- Severe lymphedema: profuse swelling with thickened skin, constant hardness, and a very large, heavy arm that is extremely obvious to others and is always present.

## 2.4 | Data collection and statistical analysis

Patients with breast cancer were asked specific questions about how their cancer affected the following domains: (1) employment/career; (2) family life; (3) social/leisure; (4) self-image; and (5) feeling about self. For patients given a diagnosis of lymphedema, information about the impact of lymphedema on employment, cost of seeing therapists, and cost of compression sleeves was collected in addition to the above domains. Data were collected between November 2014 and March 2015 using Qualtrics® survey software. Participants were directly asked about the costs of managing lymphedema reported in Australian dollars (A\$). All *P* values are 2 sided using the statistical tests for differences as specified.

## 3 | RESULTS

Of 361 patients, 209 (58%) had BC only and 152 (42%) had a diagnosis of BC+LE. The severity of lymphedema was “not noticeable” in 14 (9%), mild in 77 (51%), moderate in 55 (36%), and severe in 6 patients (4%). The time since onset of lymphedema was <5 years in 65% of cases. Demographic features of the study participants are shown in Table 1. Of note, total household income at the time of the survey was \$100 000 or more in about one-third of patients (*P* = NS).

When compression garments were used (*n* = 137), 72 (53%) were the more expensive custom-made variety and 65 (47%) were over-the-counter ready-to-wear products. Other therapies tried by the participants by stage of lymphedema are shown in Table 2. As expected, the number, complexity, and associated costs of therapies used increased as the stage of lymphedema increased. Skin care, one of the prescribed elements of complex lymphedema therapy (also known as complete decongestive therapy), was not undertaken by 38% of participants. Of the 152 patients, 48% used compression garments ranging from 14% for subclinical lymphedema to 100% for severe lymphedema ( $\chi^2$ , *P* < .001). The use of laser therapy and kinesiology tape also significantly varied by stage, but nearly all patients had previously had lymphatic drainage massage, and very few had used compression pumps or had undergone liposuction surgery.

Table 3 shows the reported out-of-pocket financial cost of lymphedema for all patients categorized by severity. The cost of compression garments formed a large proportion of the financial costs (40.1%). Visits to therapists, garment use, and costs increased as the severity of lymphedema increased. Although limited by small numbers in the

**TABLE 1** Basic demographics of patient group

		Breast Cancer (%) <i>n</i> = 209	Breast Cancer and Lymphedema (%) <i>n</i> = 152	Pearson $\chi^2$ , <i>P</i> Value
Age at time of survey (y)	<55	44.0	35.5	NS
	≥55	56.0	64.5	
Country of birth	Australia	80.4	80.3	NS
	United Kingdom	9.6	8.6	
	New Zealand	4.8	4.6	
	Other	5.2	6.5	
Marital status	Single, never married	9.1	6.6	NS
	Married, de facto	75.6	80.3	
	Separated	4.8	1.3	
	Divorced	8.1	10.5	
	Widowed	2.4	1.3	
Primary carer	No	65.6	57.9	NS
	Yes, children	18.2	22.4	
	Yes, elderly parents	5.7	3.3	
	Yes, both	3.3	5.9	
	Yes, other	7.2	10.5	
Years since treatment of breast cancer	<5	74.6	55.9	<0.001
	≥5	25.4	44.1	
Years since diagnosis of lymphedema	<5	—	65.1	—
	≥5	—	34.9	
Paid employment at diagnosis of breast cancer		77	63	.004
Total household income (A\$)	≤45 000	20.6	15.1	NS
	>45 000 to <100 000	29.2	31.6	
	≥100 000	32.1	34.9	
	Prefer not to say	18.2	18.4	

Abbreviation: NS, not significant.

**TABLE 2** Treatments used by participants with lymphedema

	Lymphedema Severity (%)					$\chi^2$ , P Value <sup>a</sup>
	All N = 152	Subclinical n = 14 <sup>b</sup>	Mild n = 77	Moderate n = 55	Severe n = 6 <sup>b</sup>	
Skin care	62	50	60	64	67	NS
Exercises	80	79	78	82	50	NS
Lymphatic drainage massage	93	100	92	85	100	NS
Compression garments	48	14	31	73	100	<.001
Laser therapy	35	14	22	56	50	<.001
Kinesiology taping	19	0	14	33	0	<.001
Pneumatic compression pumps	4	0	3	7	0	NS
Liposuction surgery	2	0	3	2	0	NS
Other	10	7	8	13	17	NS

Abbreviation: NS, not significant.

<sup>a</sup>P values used  $\chi^2$  tests to assess the associations between the use of respective treatment (yes/no) and lymphedema severity groups (moderate/severe vs subclinical/mild groups). The proportions shown above are only the "yes%" response.

<sup>b</sup>Very small sample size.

**TABLE 3** Financial costs of lymphedema (A\$)

	Lymphedema Severity					P Value <sup>a</sup>
	All N = 152	Subclinical n = 14 <sup>b</sup>	Mild n = 77	Moderate n = 55	Severe n = 6 <sup>b</sup>	
Visit to therapist						
Average visits to lymphedema therapist per year	5.8	1.9	4.5	8.8	3.5	.001
Average cost of each visit (A\$)	86	65	97	77	78	NS
Compression garment						
Average number of garments ordered per year	2.2	0.5	2.0	2.6	4.3	.001
Average cost of garments per year (A\$)	392	98	268	574	1000	<0.001
Estimate overall average expense in the last 12 months on lymphedema treatment						
Mean (A\$)	977	207	755	1433	1442	.003
SD (A\$)	425	769	1944	1160	1369	

Abbreviation: NS, not significant.

<sup>a</sup>P value used Kruskal-Wallis test for the comparison of mean ranks across the 4 lymphedema severity subgroups.

<sup>b</sup>Very small sample size.

severe group, the one exception was that the average number of visits to a therapist was only 3.5 for severe lymphedema, less than for mild or moderate lymphedema. This probably reflects the fact that severe lymphedema is often fatty and fibrotic and is nonresponsive to conservative therapies. The mean financial cost of lymphedema was A\$ 977 (SD = A\$1111; range, A\$0-12 000). The median cost was A\$525.

Further information on other financial impacts of breast cancer with or without lymphedema is shown in Table 4. Of patients with BC+LE, 80% indicated that their breast cancer diagnosis had affected them financially compared with 67% in the BC alone group ( $P < .020$ ). For patients with lymphedema, over half (56%) indicated that this specific additional diagnosis to their breast

**TABLE 4** Financial impact of breast cancer or lymphedema

	Breast Cancer Impact (%)		Lymphedema Impact (%)				
	BC Group N = 209	BC+LE Group n = 152	All n = 152	Subclinical n = 14	Mild n = 77	Moderate n = 55	Severe n = 6
Condition has affected me financially	67	80	56	43	48	67	83
I have experienced financial distress	22	22	11	0	9	13	33
I have earned less income	39	34	15	7	0	24	17
I have had to cut down my holiday budget	21	19	13	0	12	16	50
I have had to cut down expenses in social activities (eg, going out to movies or dinners)	24	24	16	14	5	22	33
I have chosen to see my lymphedema therapist in a public setting	17	13	8	7	10	13	0

Abbreviations: BC, breast cancer without lymphedema; BC+LE, breast cancer with lymphedema.

cancer-affected them financially. In general, the worse the lymphedema, the greater the financial distress (Table 4). Specific comments given about the financial impact of lymphedema are shown in Table 5 (Supporting Information).

Twenty-five patients (16.4%) had an episode of cellulitis in the past year. Twelve of 152 patients (7.9%) were admitted to hospital owing to cellulitis for an average admission stay of 4.8 days (range, 1-10 d). The total number of admission days was 57 for the 12 patients admitted. The average number of days in hospital for cellulitis associated with mild or moderate lymphedema ( $n = 3$ ) was 4.0 versus 5.0 days for moderate/severe lymphedema ( $n = 9$ ). The incidence of cellulitis was 7 (7.7%) in 91 patients with subclinical or mild lymphedema compared with 18 (29.5%) of 61 patients with moderate to severe lymphedema ( $P < .001$ ).

## 4 | DISCUSSION

Lymphedema is a feared complication of breast cancer and impacts physical, functional, psychological, and social well-being of patients after treatment. However, existing scholarship is in the early stages of development regarding many aspects of this condition. Our study shows that, when compared with breast cancer survivors without lymphedema, individuals living with lymphedema are worse off in terms of out-of-pocket financial costs, with a substantial proportion of these costs coming from compression garments. It is critical that the issue of out-of-pocket expenses and other costs associated with lymphedema are understood and evaluated to help shape policy for health insurers and government.

The recommended best practice for care and treatment of lymphedema and chronic edema includes the following: compression (garments and/or bandaging); meticulous skin care; education; manual lymphatic drainage; and exercise. These interventions are expensive in terms of out-of-pocket costs and time off work or away from family. In our study, 38% of patients were not undertaking any skin care, a fundamental component of complete decongestive therapy found to reduce cellulitis and admission costs from cellulitis.<sup>17</sup>

There have been some studies conducted in the United Kingdom and the United States that estimate the health care costs of lymphedema, but none of these studies estimated the financial cost borne by women.<sup>12,15,18</sup> Out-of-pocket expenses typically relate to the costs of seeing doctors or therapists, the purchase of over-the-counter or more expensive custom-made compression garments, the use of skin creams and the prescription and purchase of antibiotics, and often copayments after admission to hospital for cellulitis. Some idea of the prevalence of these events was reported by Moffat<sup>18</sup> in the United Kingdom, where 27% of 823 patients with edema were admitted to hospital for antibiotic treatment; 32% received some form of compression bandaging; and 29% had an infection in the past 12 months. The mean length of stay was 12 days at a mean cost of £2300. Of note, 80% had taken time off work, and 8% had to give up work. This is comparable with our study, in which 25 patients (16.4%) had an episode of cellulitis in the past year and 12 of 152 patients (7.9%) were admitted to hospital because of cellulitis for an average admission stay of 5.6 days (range, 1-10 d). Further, the incidence of cellulitis was 7.7%

in 91 patients with subclinical or mild lymphedema, compared with 29.5% of 61 patients with moderate to severe lymphedema ( $P < .001$ ).

The National Hospital Cost Data Collection is the annual collection of public hospital cost data in Australia. In 2014, the average cost per admission for cellulitis was divided into less severe (80.6%) and more severe cases (19.4%), with an average cost per admission of A\$4102 and A\$9605, respectively.<sup>19</sup> In our series, this would have equated to a total cost of \$98 751 for the 12 patient admissions (3 less severe and 9 more severe) and excludes 13 patients who were not admitted but had to pay for medical visits and antibiotics and had to take time off work.

A qualitative study from Canada reported aspects of abandonment described by some participants because of the lack of financial support available to cover the costs of treatment strategies. Compression garments were expensive to buy, and a number of participants did not have insurance. Those with insurance policies stated that there was insufficient coverage for sleeve replacement costs. Participants stated that the need for frequent cleaning caused compression garments to lose elasticity and require regular replacement. Several participants found the cost of compression pumps and massage therapy prohibitive.<sup>20</sup> In another study, issues influencing self-care, including the high cost of and insurance coverage for supplies, were reported as slight to major problems by at least 20% of the participants.<sup>21</sup>

In our study, when compression garments were used by 137 women, 53% were the more expensive custom-made variety and 47% were over-the-counter ready-to-wear products. A common theme among patients was the expense of garments and the lack of financial reimbursement from the government or private health insurance funds.

There have been limited studies on the impact of lymphedema on financial costs borne by the patient. Gordon et al<sup>22</sup> longitudinally examined economic outcomes (costs and lost income) for 287 Australian patients with breast cancer up to 18 months after their diagnosis. On average, patients incurred US\$245 in out-of-pocket financial costs, but compression sleeves for lymphedema were only one component of these costs (ie, wigs, customized bras, etc, were also included in this estimate). A previous US study demonstrated that cancer survivors were more likely to report a high annual out-of-pocket burden than individuals without a history of cancer. This burden was more common among cancer survivors compared with those without a diagnosis of cancer, those without private insurance, and those not working. Among cancer survivors, out-of-pocket burden was associated with being unable to obtain necessary medical care and delaying necessary medical care. Our experience is that many patients still wear a compression sleeve even when it has significantly diminished pressure to delay the expenditure for a replacement.<sup>23</sup>

A limitation of our study is that it used a cross-sectional rather than longitudinal survey design. As a result, we could not explore whether these financial costs have increased over time. In addition, as we asked participants to self-report on the impact of lymphedema over and above breast cancer, the study could be affected by recall bias. However, a cross-sectional design and the use of an online survey allowed for a good sample size, and indicators of lymphedema status were included, such as the number of symptoms

and time since diagnosis. We also only included patients who had seen a lymphedema therapist. Further, our study was not a formal cost-utility health economics study and may not be generalizable to other health jurisdictions, particularly those with better support for patients with lymphedema such as Scandinavia. Cheville et al<sup>24</sup> argued that lymphedema is best estimated as a chronic disease by utility values given its chronic nature and treatment that enhances rather than extends patients' lives. To adequately review these factors, we are planning a prospective study to further differentiate the impact on finances from lymphedema versus the impact from breast cancer.

These findings have implications for clinical practice, future research, and policy-making. Health professionals involved in the care of patients with lymphedema must be aware that these women are at risk of experiencing not only psychological distress and body image disturbance<sup>25</sup> but also potential finance-related stress. Out-of-pocket costs cause some patients who are under financial stress to delay replacing their compression sleeves when they lose pressure and/or delay seeing a lymphedema therapist, despite the benefit of treatment in reducing the incidence of cellulitis.<sup>26,27</sup> Our study shows that as lymphedema becomes more advanced, episodes of cellulitis increase, further compounding costs to the patient and the health system. The lack of both appropriately trained and funded therapists and reimbursement for treatment is false economy in the long-term for patients whose lymphedema acts as a daily reminder of their previous breast cancer treatment.

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## SUPPORTING INFORMATION

Additional Supporting Information may be found online in the supporting information tab for this article.

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