BCNA Research Report

Lymphoedema services in Victoria

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Introduction

Breast cancer-related lymphoedema is a swelling of the arm, hand, breast or other area of the body which can develop in women (or men) diagnosed with breast cancer whose lymph nodes have been removed or damaged.\(^1\) Lymphoedema may develop immediately after breast cancer treatment or years later. Individuals affected by breast cancer have a lifetime risk of developing lymphoedema.\(^2\) It is estimated that approximately 20 per cent of people diagnosed with breast cancer will develop breast cancer-related lymphoedema.\(^3\)

The development of breast cancer-related lymphoedema can have a significantly negative impact on women’s physical and emotional wellbeing and overall quality of life.\(^4\) Women may experience ongoing pain, tightness and aches, a reduced range of motion in the area of the body affected by lymphoedema, as well as ongoing infections, such as cellulitis, inflammation\(^5\) and fatigue.\(^6\) Lymphoedema is also associated with stress, anxiety, depression, body image issues and decreased self-esteem.\(^7\) Importantly, early identification of lymphoedema and treatment may prevent lymphoedema from becoming chronic and ‘irreversible’.\(^8\)

Recently, a number of public lymphoedema services in Victoria have closed and Breast Cancer Network Australia (BCNA) has received reports that other services are not taking new referrals. To understand more about the impact of these closures on Victorians, BCNA conducted an online survey. This report provides a summary of findings from this research.

Method

The survey was open to BCNA members of Review & Survey Group living in Victoria (n = 582). The survey tool was developed and approved by BCNA (see Appendix A). Kate Rogers, a member of the Board of the Australasian Lymphology Association, reviewed the survey and provided feedback. The survey contained 32 questions plus 5 demographic questions. Most were multiple choice or rating scale questions, with 4 additional open-ended questions.

The survey was administered via SurveyMonkey and was open from 15 June 2016 to 25 July 2016 (40 days in field). An email invitation was sent to 582 members of the Review & Survey Group with a link to the survey included. A reminder email was sent on 18 July 2016.

Raw survey data was downloaded from SurveyMonkey into Excel for analysis. Open-ended responses were thematically analysed by one researcher.

Please note that although proportions (%) have been provided in the results section, less than 100 participants completed the survey. Thus generalising these results to the entire population of Australians with breast cancer should be done with caution.
Key Findings

This section outlines key findings from the survey. They are presented under five areas of interest: (1) participant profile, (2) participants’ experiences of lymphoedema, (3) access to Victorian lymphoedema services, (4) information about lymphoedema and (5) financial impact of lymphoedema.

Participant profile

In total, 90 members completed the survey, equating to a 15.5% response rate.

Most participants were aged 50 to 69 years, lived in a metropolitan area of Victoria (n = 54, 62.8%), and spoke English as their main language spoken at home. In total, 11.6% participants identified as having a disability.

Just over 70% of participants were diagnosed with early breast cancer (n = 64), while 4.4% of participants were living with metastatic breast cancer.

Nearly one third of participants were diagnosed five to 10 years ago (n = 27, 30%) and 34.4% (n = 31) were diagnosed 10 or more years ago. Eleven per cent of participants (n = 10) were diagnosed more than three and up to four years ago, 10.0% of people (n = 9) were diagnosed more than one and up to two years ago, 8.9% (n = 8) were diagnosed more than two years to three years ago and 5.6% (n = 5) were diagnosed in the past 12 months.

The majority of participants reported having received treatments which may have increased their risk of lymphoedema - 80% of participants (n = 72) had an axillary clearance. Many participants also had radiotherapy in the area of the armpit (n = 41, 45.6%), chest (n = 53, 58.9%) and/or neck (n = 19, 21.1%). Approximately a quarter of participants (n = 23, 25.6%) had more than 20 lymph nodes removed.

It should be noted that the proportion of participants who indicated they had an axillary clearance is high at 80 per cent. This may be because a large number of survey participants were diagnosed and treated for their breast cancer before sentinel node biopsy became standard care. As Figure 1 indicates, over two thirds of participants who said they had received an axillary clearance were diagnosed 5 or more years ago. There may also have been some confusion about the term ‘axillary clearance’.

Despite the number of participants who received treatments which may have increased their risk of lymphoedema, over 80% (n = 75, 83.3%) indicated that no one had measured the distance around their arm or fingers prior to their breast cancer surgery and 71.1% (n = 64) of participants said a device to measure the flow of fluid had not been used before or after surgery.
Participants’ experiences of lymphoedema

Development of lymphoedema

In total, 73% (n = 65) of the 89 participants who responded to the question reported that they had been diagnosed with lymphoedema following their treatment for breast cancer.

Figure 2 shows the length of time between treatment and developing lymphoedema. Just over half of the participants developed lymphoedema within 12 months of finishing treatment. However, approximately 9% (n = 6) developed lymphoedema between three years and 15 years after treatment.

Figure 2: Length of time before lymphoedema developed

Q17. How long after your breast cancer treatment did you develop lymphoedema? (n = 65)
**Symptoms of lymphoedema**

Participants who were diagnosed with lymphoedema experienced a range of physical symptoms. Over 90% experienced swelling in their arm, breast, hand, shoulder or chest area and 81.5% felt a heaviness, fullness, tightness or discomfort in their arm or breast area. Nearly two-thirds of participants experienced aching, pain or tension (n = 41, 63.1%).

**Table 3: Signs and symptoms of lymphoedema experienced by participants (n = 65)**

<table>
<thead>
<tr>
<th>Symptom</th>
<th>Number</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Swelling in arm, breast, hand, shoulder or chest</td>
<td>60</td>
<td>92.3%</td>
</tr>
<tr>
<td>Feelings of heaviness, fullness, tightness or discomfort in arm or breast area</td>
<td>53</td>
<td>81.5%</td>
</tr>
<tr>
<td>Aching, pain or tension in arm, hand, shoulder, chest or breast area</td>
<td>41</td>
<td>63.1%</td>
</tr>
<tr>
<td>Difficulty getting jewellery on or off, such as rings, bracelets or watches</td>
<td>35</td>
<td>53.9%</td>
</tr>
<tr>
<td>Difficulty fitting arm into shirt that used to fit well</td>
<td>28</td>
<td>43.1%</td>
</tr>
<tr>
<td>Loss of flexibility or movement in the joints near where you had surgery (e.g. in shoulder, hand or wrist)</td>
<td>24</td>
<td>36.9%</td>
</tr>
<tr>
<td>Feeling like your skin is warmer than usual</td>
<td>20</td>
<td>30.8%</td>
</tr>
<tr>
<td>A change to texture of skin (e.g. tightness, hardness, redness)</td>
<td>18</td>
<td>27.7%</td>
</tr>
<tr>
<td>Other</td>
<td>7</td>
<td>10.8%</td>
</tr>
</tbody>
</table>

* Note: Multiple responses possible thus percentages do not add up to 100%

**Severity of lymphoedema**

The majority of participants developed mild (stage 1) lymphoedema (n = 46, 70.8%). However, 12 respondents (18.5%) developed moderate lymphoedema and two respondents experienced severe (stage 3) lymphoedema (3.1%).

**Usefulness of treatment**

Participants emphasised the usefulness of treatment in managing their lymphoedema. The majority of participants reported that the treatments they received had been 'very useful' (n = 25, 38.5%) or 'useful' (n = 32, 49.2%) in relieving the symptoms of lymphoedema.

_I have been able to manage my lymphoedema and prevent it from worsening as a result of taking the advice of my physiotherapist._

When asked what treatments they had received, participants reported a wide range including:

- Lymphatic drainage massage by a qualified lymphoedema practitioner (n = 53, 81.5%)
- Lymphatic drainage massage by self or partner (n = 43, 66.2%)
- Exercise program guided by a health professional (n = 42, 64.5%)
- Ready-made compression garments (n = 40, 61.5%)
- Custom-made compression garments (n = 31, 47.7%)
- Information session about lymphoedema (n = 19, 29.2%)
- Compression bandaging (n = 10, 15.4%)

I asked my oncologist to refer me to a lymphoedema practitioner, and subsequently have had a number of consultations which have been extremely useful. I haven't specifically been treated with CLT, I don't think, but have undergone most of the treatments described over the past twelve months.

Access to Victorian lymphoedema services

Of the 65 participants who had been diagnosed with lymphoedema, 20% (n = 13) reported having difficulty accessing services in Victoria, either because the service they wanted to attend had been closed (n = 10, 15.4%) or the service was not taking new referrals (n = 3, 4.6%).

Without being able to access this treatment through the health system, I've had to find private therapists, when they have moved or stopped their practices, I have often been left without treatment for a considerable time while I find someone else.

Eastern Health shut the service very suddenly and has left a lot of people in the outer eastern suburbs of Melbourne struggling.

I phoned a few recently as need some treatment. Got an appointment to see someone tomorrow but have waited for nearly 4 weeks for the appointment. Private appointment.

Of the 65 participants who had been diagnosed with lymphoedema, 26.2% of participants (n = 17) said they had received private treatment but would have preferred to go to a public service if there had been a public service available in their area.

Would love to able to access public facility so as not to rely on private health fund.

As Figure 3 shows, waiting times to access treatment varied, but the majority of respondents (n = 49, 75.4%) were able to access treatment within one month of being referred to treatment.

However, seven respondents had to wait one month or longer between their referral and treatment. Five respondents also made the point that they had not received a referral from a health professional; instead, they had to initiate treatment themselves.

Was never referred by a health practitioner. Heard about it from other women.

Was not referred, I found it myself after being told I had breast lymphoedema by medical oncologist at review. I knew a lymphoedema nurse (previous work colleague) who had gone into private practice after Eastern Health suddenly shut down the clinic she ran at Yarra Ranges Health, and I contacted her.
Information about lymphoedema

Unmet information needs

Participants were asked about the lymphoedema information they may or may not have received prior to beginning breast cancer treatment.

While 43 participants (47.8%) reported having received information about lymphoedema before starting treatment, 37 respondents (41.1%) said they had not received any information about lymphoedema before treatment commenced.

Of the 37 participants who received no lymphoedema-related information, 28 participants (75.7%) went on to develop breast cancer-related lymphoedema. While 22 of these participants were diagnosed 5 to 10 years ago (n = 13, 46.4%) or more than 10+ years ago (n = 9, 32.2%), six participants (21.4%) who developed lymphoedema but who had received no information about lymphoedema before starting treatment had been diagnosed in the past 4 years.

> It was because of my concerns and a private lymphoedema physiotherapist that I was diagnosed.

> I had surgery 8 years ago next month. No-one spoke to me about lymphoedema following surgery, chemotherapy or radiotherapy. Several months later when my hand and arm were noticeably swollen, a work colleague recommended a lymphoedema therapist.

Also, 6 of the 28 participants who had received no information prior to treatment, but who ended up developing lymphoedema, developed lymphoedema they described as either ‘moderate’ or ‘severe’.

Who provided information about lymphoedema?

Breast care nurses were central in providing participants with information about lymphoedema prior to breast cancer treatment. Of the 43 participants who received information about lymphoedema, almost three-quarters received this information from a Breast Care Nurse (n = 32, 74.4%).
Other participants received information from their surgeon (n = 15, 34.9%), physiotherapist (n = 7, 16.3%), lymphoedema practitioner, (n = 6, 14.0%), chemotherapy or oncology nurse (n = 5, 11.63%), or oncologist (n = 4, 9.3%) or radiation oncologist (n = 4, 9.3%). One respondent received information from a GP. Respondents could select multiple responses for this question.

When asked about the extent their information needs were met, approximately one quarter of participants who had received lymphoedema information indicated they received all (n = 11, 25.6%) or a large amount (n = 13, 30.2%) of the information they needed (see Figure 4). However, 18 participants received only some (n = 13, 30.2%) or a little bit (n = 5, 11.6%) of the information they needed.

Figure 4: The extent to which lymphoedema information needs were met

Information topics

Participants who received information about lymphoedema reported receiving information about a range of topics, particularly topics relating to how to identify lymphoedema, how to reduce the risk of developing lymphoedema and what to do if lymphoedema develops. Table 4 sets out the range of topics about which participants received information.

Table 4: What information were you given about lymphoedema? (n = 43)

<table>
<thead>
<tr>
<th>Topic</th>
<th>Number</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>What lymphoedema is</td>
<td>41</td>
<td>95.3%</td>
</tr>
<tr>
<td>What are the signs / symptoms of lymphoedema</td>
<td>37</td>
<td>86.0%</td>
</tr>
<tr>
<td>How to lessen the risk of developing lymphoedema</td>
<td>32</td>
<td>74.4%</td>
</tr>
<tr>
<td>What to do if I noticed swelling or other signs</td>
<td>26</td>
<td>60.5%</td>
</tr>
<tr>
<td>How common lymphoedema is</td>
<td>24</td>
<td>55.8%</td>
</tr>
</tbody>
</table>
Financial impact of lymphoedema

The survey also asked participants about the financial impact of lymphoedema treatment they may have received. Figure 5 sets out the out-of-pocket costs participants indicated they pay for lymphoedema treatment per year.

**Figure 5: Costs of lymphoedema treatment each year**

I only went to physio on one GP plan (I think that was 8 appointments). Cost up to $750.

Last year < $250 due to Medicare Safety Net; this year it will be somewhat over $250.

One participant reported having to stop receiving treatment due to the financial costs.

When asked whether the costs of treatment put pressure on their family finances, 20 of the 47 respondents who answered the question said treatment put ‘a little pressure’ on their finances and 18 indicated it put ‘no pressure’ on their finances.

I have not had to pay for any services. I attended clinics in public hospitals approximately every 6 months for measurement and a chat. It was felt that I could
manage my lymphoedema confidently and have not attended a clinic for more than 12 years.

However, three respondents indicated lymphoedema treatment put ‘a lot of pressure’ and five respondents said it put ‘moderate pressure’ on their finances. One respondent was unsure.

*Lymphedema is for life, so the financial cost is a worry after suffered financial strain from the breast cancer treatment & scaling back my working hours*
Conclusions

This section outlines the conclusions that relate to the key findings of this research.

Conclusion 1: More lymphoedema services are needed

Because of the benefits of early detection of breast cancer-related lymphoedema and early treatment, it is critical that all individuals who develop lymphoedema due to breast cancer are able to easily access affordable, high quality lymphoedema services and supports.

A total of 20% of participants in this survey reported experiencing difficulties accessing services in Victoria, either due to the service they wanted to access being closed or not taking new referrals. In addition, 26.2% of participants indicated that they had received private treatment, but would have preferred to go public but there were no services available in their area.

This survey indicates that a proportion of Victorians affected by breast cancer-related lymphoedema are experiencing difficulty accessing lymphoedema services, and some may be accessing private treatment services not because they prefer to, but due to a lack of services in their local area.

Conclusion 2: Lymphoedema treatment is effective

The majority of participants reported that the treatments they had received had been ‘very useful’ (38.5%) or ‘useful’ (49.2%) in relieving the symptoms of lymphoedema. This is in line with research which has found that treatment for lymphoedema is effective and highlights the need for lymphoedema treatments to be widely available, easy to access and affordable.

Conclusion 3: Gaps in lymphoedema information provision

Having access to comprehensive information about lymphoedema may assist individuals to implement strategies to reduce their risk of lymphoedema, identify lymphoedema at an early stage, seek appropriate treatment or adopt self-management strategies that can help to address lymphoedema they may be experiencing and prevent it from becoming worse.

Despite the importance of individuals having access to high quality information, 37 out of 90 survey participants indicated that they had not received any information about lymphoedema before their breast cancer treatment commenced.

An even greater concern is that 28 of the 37 participants who had received no information about lymphoedema went on to develop lymphoedema following their breast cancer treatment.

For women at risk of breast cancer-related lymphoedema, a lack of information about what lymphoedema even is will only hamper their ability to make informed choices about treatment and care. It also impedes their ability to recognise signs and symptoms of lymphoedema and seek treatment at an early point.
While some may argue it is likely that the participants who did not receive information about lymphoedema were diagnosed many years ago and that this is an issue of the past, 6 of the 37 participants who received no information about lymphoedema but developed it following their breast cancer treatment were diagnosed with breast cancer in the past four years.

It is imperative that comprehensive, high quality written and/or verbal information about breast cancer-related lymphoedema be provided to all individuals at risk of lymphoedema as a routine component of breast cancer treatment and care.

**Conclusion 4: Gaps in screening to identify lymphoedema early**

The survey also found that, despite many participants receiving breast cancer treatments that were likely to have increased their risk of lymphoedema, such as an axillary clearance or radiotherapy to the chest, armpit, and/or neck, that over 80% of participants reported that no one had measured the distance around their arm or fingers prior to their breast cancer surgery and 71.1% of participants said a device to measure the flow of fluid such as the L-Dex machine had not been used before or after surgery.

A more widespread use of devices to measure the flow of fluid such as an L-Dex machine before and/or after surgery or the routine measuring of the distance around the arm or fingers is likely to ensure that more cases of lymphoedema are detected early and that treatment is able to be given at an earlier point before symptoms become severe.

**Conclusion 5: Cost of lymphoedema treatment prohibitive for some**

While the majority of participants in this survey did not seem to find the financial impact of lymphoedema treatment to be too significant, eight participants reported spending between $500 and $1000 each year, four paid between $1000 and $1500 a year and one participant reported spending between $2500 and $3000 per year. One participant also indicated stopping treatment for lymphoedema due to the cost.

The availability of affordable treatment for lymphoedema is necessary in ensuring that all individuals who develop lymphoedema as a result of breast cancer treatment are able to access the treatment and support that is most appropriate to their individual circumstances.