Understanding the acceptability and feasibility of a regional lymphoedema surveillance programme: a pilot study



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Background: Lymphoedema is a common complication for breast cancer survivors. Early detection and treatment reduces costs and improves outcomes. **Aim:** To determine the acceptability and feasibility of a lymphoedema surveillance programme (LSP) for breast cancer patients and breast clinic staff in rural and regional areas. **Methods:** All patients diagnosed with breast cancer were invited to participate. Data collected prior to surgery included patient characteristics, Lymphoedema Index and circumferential measurements. Staff and patients were asked to complete a survey to rate their understanding and experience of the LSP. **Results:** Most patients — 91% (32/35) — and all staff (9/9) completed the survey. Overall, staff and patients had a very good experience with the LSP. **Conclusion:** The LSP was successfully implemented, was acceptable and feasible for staff and patients.

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Breast cancer is the most commonly diagnosed cancer in women in Australia and it is estimated that one in eight women are diagnosed before the age of 85 (Australian Institute of Health and Welfare, 2017). Breast cancer survivorship is continuing to improve (Australian Institute of Health and Welfare 2017), resulting in a greater prevalence of complications. Breast cancer-related lymphoedema (BCRL) is a common sequelae that can occur in people being treated for breast cancer, with an estimated incidence of 20% (Cancer Australia, 2017).

BCRL is the accumulation of excessive amounts of protein-rich fluid in the arm or trunk as a result of trauma to the lymphatic system, such as surgery or radiation, or as a result of the cancer itself (Cancer Australia, 2017). Lymphoedema is categorised into four stages according to the degree of swelling as well as the presence of permanent tissue changes (International Society of Lymphology Executive Committee [ISLEC], 2016). Stage 0 is a latent or sub-clinical state, where swelling is not clinically evident, but lymphatic transport is impaired; whereas stage 3 is associated with significant limb volume increases, tissue changes and reduction in function (ISLEC, 2016).

There are multiple factors that increase the risk of developing BCRL, including — but not limited to — the extent and type of surgery, radiation treatment, chemotherapy and high body mass index (BMI) (Clark et al, 2005; Shih et al, 2009; Shah et al, 2012). Patients with BCRL have a lower quality of life and reduced arm function when compared with breast cancer survivors without lymphoedema (Lopez Penha et al, 2016). If not managed appropriately in the initial stages, BCRL can become a progressive, chronic and costly complication of breast cancer (Shih et al, 2009).

Early detection and treatment of BCRL may prevent the irreversible degenerative changes that occur in the lymphatic vessels, such as fibrosis (Ramos et al, 1999). BCRL needs to be diagnosed and treated as early as possible to optimise patient outcomes and reduce the cost of treatment. The majority of patients will present with evidence of BCRL in the 24 months following surgery, highlighting the need for surveillance during this period (Clark et al, 2005; Hayes et al, 2008).

Diagnosis of sub-clinical and clinical lymphoedema can be missed 40–50% of the time if baseline measurements are not taken prior to surgery (Sun et al, 2016). Circumferential measurements of the arm, in conjunction with patient self-report and water displacement, have been the traditional methods for diagnosing lymphoedema. These two methods fail to

diagnose BCRL at the subclinical level (ISLEC, 2016) as they are not sensitive enough to detect the early changes in extracellular fluid volumes (Levenhagen et al, 2017). Subclinical lymphoedema can be reliably and accurately detected using bioimpedance spectroscopy, as it detects small changes in extracellular fluid when clinical oedema is not evident (Laidley and Anglin, 2016). It is a quick, non-invasive method endorsed by the Australasian Lymphology Association (ALA), requires minimal training and can easily be incorporated into routine follow-up care (Cornish et al, 2001; ALA, 2012). It has good intra- and inter-rater reliability (Jain et al, 2010), high sensitivity and specificity, and can predict the onset of lymphoedema up to 10 months before clinical signs appear (Cornish et al, 2001).

Despite the growing evidence supporting the early screening of BCRL, it has not been widely implemented (Blaney et al, 2015). A feasibility study reported high recruitment (85.7%) and retention (83.8%) rates in a screening programme, suggesting that breast cancer survivors are interested in and value surveillance (Blaney et al, 2015). Lymphoedema assessments as part of the routine follow up visit for breast cancer survivors help reduce patients' emotional, physical and financial burdens (Hayes et al, 2008). The inclusion of surveillance as part of routine care is achievable and acceptable to survivors of breast cancer (Blaney et al, 2015).

Lymphoedema surveillance programme: background

There is the potential for substantial reduction of costs with the implementation of a lymphoedema surveillance programme (LSP) compared with the traditional model of care, given it promotes early diagnosis and a reduction in morbidity (Cheville et al, 2012). Screening and surveillance of BCRL is generally undertaken by physiotherapists or occupational therapists, however, Cheville and colleagues (2012) suggest there may be a growing role for allied health assistants (AHAs) to perform the screening process in order to reduce overall costs of the programme. When there is an indication for a diagnosis of BCRL during screening, a referral can be made to a qualified lymphoedema practitioner for an appropriate management plan (ALA, 2012).

The involvement of all stakeholders, including staff and patients, is fundamental to the uptake and effectiveness of a LSP. Developing a model that is patient-centred and provided by skilled and knowledgeable clinicians is crucial to optimise a patient's quality of life, as well as their acceptance of the programme (Fu et al, 2012; 2016).

Prior to the implementation of the LSP, the management of BCRL was based on referral to physiotherapy by medical practitioners or nurses. Referrals were made after clinical signs and symptoms were identified, and often when they were already well established. To identify and manage BCRL early and to optimise outcomes, a LSP was developed to screen patients, obtain pre-operative measures, and provide regular screening for 2 years post-surgery. The LSP was developed with consumer consultation and implemented in conjunction with the surgical breast clinic (SBC). The LSP took place in a regional health service that covers a population of 230,000 living within a 48,000 km^2 area. The health service has 294 acute and sub-acute beds and sees 80–100 new breast cancer patients each year.

The primary aim of this study was to determine the acceptability and feasibility of a LSP for patients with breast cancer and for staff members working in the SBC.

Methods

This study was conducted in a large hospital in Victoria, Australia, which has a regional integrated cancer service. All patients with newly-diagnosed breast cancer seen in the SBC were eligible to participate in the LSP, except for those receiving neo-adjuvant chemotherapy.

The LSP pathway is shown in *Figure 1*. The first screening session was conducted in conjunction with the weekly SBC clinic. Patients were initially assessed when a diagnosis of breast cancer was confirmed and prior to their planned surgery. Patient characteristics and baseline limb measurements were recorded. Patients received education regarding the signs and symptoms of lymphoedema, strategies for reducing their risk of developing lymphoedema, and the lymphoedema clinic contact information. Patients were to be screened at 3, 6, 12, 18 and 24 months post-surgery when they returned for monitoring. Those with follow-up measures indicating potential BCRL or who were experiencing symptoms of BCRL were referred to the lymphoedema therapist for appropriate ongoing management.

Data were collected on patient demographics, medical and patient characteristics. Objective measures taken at each session included Lymphoedema Index (L-Dex) values from bioimpedance spectroscopy and circumferential measurements of both the affected and non-affected arm.

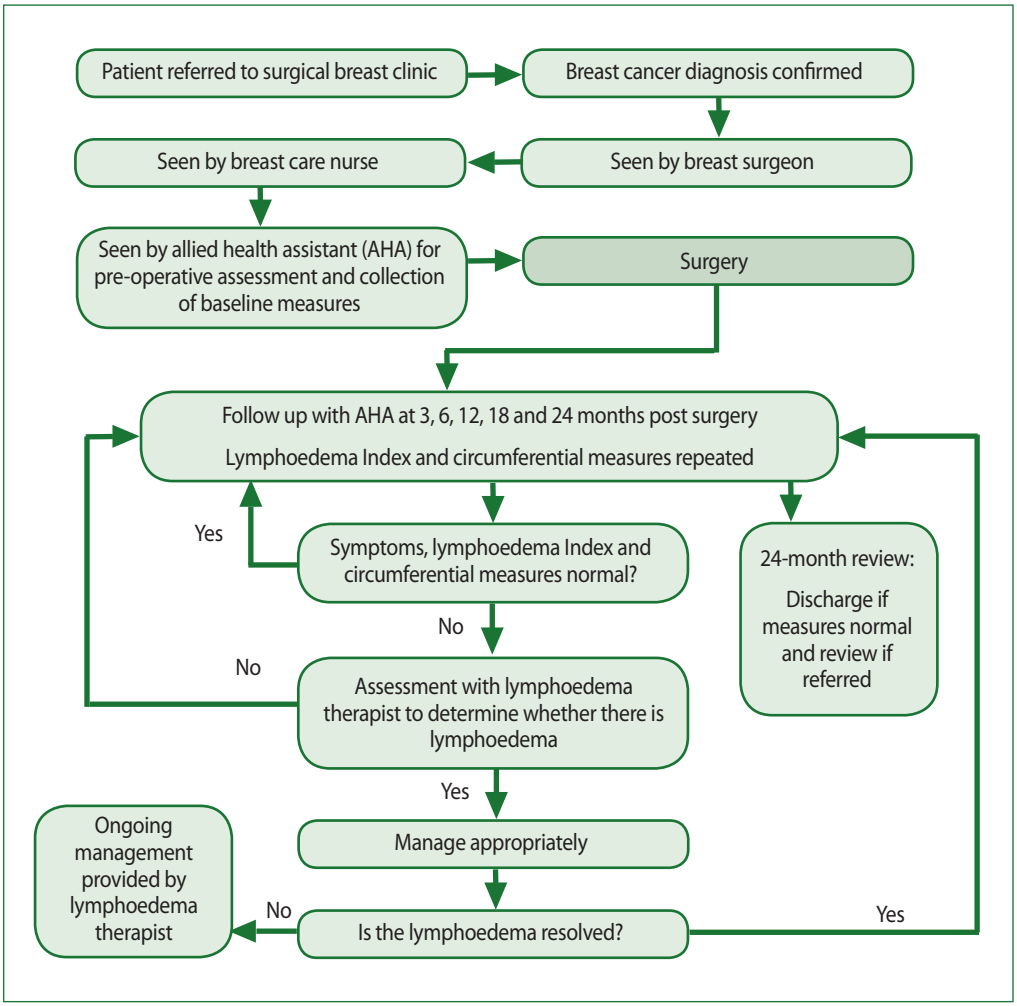

Figure 1. Lymphoedema surveillance programme treatment pathway.

At subsequent screening sessions, indicators for referral and assessment by a lymphoedema therapist included:

- L-Dex values above the normal range of 10 units
- Increase in L-Dex of 10 units from baseline
- Upward trend in L-Dex values
- Circumferential differences that had increased from baseline.

Data were collected by the physiotherapist or AHA at the initial breast clinic visit and prior to planned surgery. To ensure reliable data collection and competent independent practice, the AHA was trained via demonstration, close supervision and feedback from the physiotherapist. Data were analysed using descriptive analysis.

Surveys using a Likert scale ranging from 0 (strongly disagree) to 5 (strongly agree) and open-ended questions were used to assess patient and staff perceptions of the LSP. Patients were asked to rate their level of understanding of the LSP, the education given to them, and their overall experience. They were also asked when they would prefer their measurements were taken, i.e. when attending the breast clinic or on a separate day. Staff were asked to rate their understanding, satisfaction with and experience working alongside the LSP.

Ethical approval for this study was obtained from the Ballarat Health Services & St. John of God Human Research Ethics Committee (Reference: LNR/16/BHSSJOG/52).

Results

Over the 6-month data collection period (October 2016 to March 2017), 41 patients with newly-diagnosed breast cancer were treated in the SBC. Two were excluded from the LSP as they were receiving neo-adjuvant chemotherapy and four were unable to participate due to lack of LSP staff availability.

The data collected are presented in *Table 1*. All patients were female, with a mean age of 60.9 years. Most patients lived within 20 km of the hospital, with 22.9% living further away. Of the

Table 1. Patient characteristics and baseline objective measures* (*n*=35).	
Characteristic/objective measure	
Age in years, mean (standard deviation)	60.9 (14.29)
Female gender	35 (100%)
Body mass index:*	
■ Underweight (<18.5)	0 (0.0%)
■ Normal (18.5–25)	6 (21.4%)
■ Overweight (25–30)	10 (35.7%)
■ Obese (>30)	12 (42.8%)
Dominant limb at risk	20 (57.1%)
Distance from hospital:	
■ 0–20 km	27 (77.1%)
■ 21–50 km	2 (5.7%)
■ 51–100 km	5 (14.3%)
■ >100 km	1 (2.9%)
Breast surgery type:	
■ Mastectomy	14 (40.0%)
■ Breast-conserving surgery	20 (57.1%)
■ Prior mastectomy and reconstruction	1 (2.9%)
Axillary lymph node surgery type:	
■ Axillary clearance	11 (31.4%)
■ Sentinel node biopsy	24 (68.6%)
Initial screen	
Bioimpedance analysis:	
■ Negative lymphoedema index scores	16 (45.7%)
■ Measures outside the normal range	2 (5.7%)
Circumferential measures:	
■ >2 cm difference outside normal range	2 (5.7%)
*Data missing from 7 patients	

28 patients whose BMI was recorded, 22 (78.6%) were overweight or obese. More than half of the patients (57.1%) underwent breast-conserving surgery and 68.6% had a sentinel node biopsy. The differences between upper limb circumferential measures ranged from -4.6 to +2.9 cm, and 45.7% of patients had negative L-Dex scores at baseline.

Patient survey results

The survey was completed by 32/35 (91%) patients. The results are given in *Table 2*. Most patients (94%) indicated that they preferred to complete their assessment on the day they attended the SBC.

Common themes in patients' comments were that the LSP was informative and well co-ordinated. Patient comments included: "I appreciate the co-ordination and teamwork" and: "Very happy with the information and co-ordination of appointments."

Staff survey results

The survey was completed by all nine staff members who were working in the SBC, including four surgical consultants, one surgical registrar, two specialist breast care nurses and two breast clinic nurses. The results are given in *Table 3*.

Staff members found the LSP to be invaluable to patients undergoing treatment for breast cancer. They felt it was an area that was previously being "underserved" and was a "well-needed service". They also reported receiving positive feedback and remarks from patients who participated in the LSP, saying the programme was "very much appreciated by the patients and staff" and a "positive experience" for patients.

Discussion

Early identification and management of lymphoedema is important to ensure the best outcomes for breast cancer survivors. This study evaluated the perceptions of patients and staff of a LSP for people newly diagnosed with breast cancer. Patients reported high levels of overall satisfaction with the LSP and found the information provided about lymphoedema useful. All staff members working in the SBC reported that the LSP was beneficial for patients. They were also positive about the LSP running in conjunction with the clinic. The results demonstrate that a LSP for breast cancer patients that is run in conjunction with a SBC is both feasible and acceptable for staff and patients.

In this study, the patients reported that the LSP was informative and that they understood its purpose. A literature review by Binkley et al (2012) reported that many patients find the risk of developing BCRL more daunting than the breast cancer itself. The literature also described patients reporting frustrations with the inconsistency of information, education and support provided, as well as a lack of follow-up in regards to the development of BCRL (Lee et al, 2010; Binkley et al, 2012). The inclusion of the LSP within the SBC provided a safe place where patients could receive consistent information and access support if required. Patients found the LSP to be very informative and the majority found the information clear and helpful, suggesting the LSP may reduce patients' anxieties and, knowing that their BCRL status is being monitored, indirectly improve their quality of life.

Patients appreciated the coordination of the LSP with their SBC visits. Nearly a fifth lived

Table 2. Patient survey results (score range: 0–5), *n*=32	
Statement	**Mean score (SD)**
I understood why my arms were measured	4.69 (0.82)
I was provided with clear explanations throughout my assessment	4.78 (0.49)
I found the information provided about lymphoedema was helpful for me	4.69 (0.69)
My questions about lymphoedema were answered	4.68 (0.59)
At the end of my assessment, it was clear to me when I should be remeasured	4.72 (0.77)
Overall experience of the lymphoedema surveillance programme in the surgical breast clinic	4.75 (0.95)

more than 50 km away from the SBC. Having the LSP run on the same day as the SBC, therefore, reduced travel time and expenses compared with attending clinics on separate days. The convenience of scheduling was also identified as a benefit, with the majority of patients preferring to be seen in both SBC and LSP on the same day.

To the best of the authors' knowledge, this is the first study to investigate the acceptability and feasibility of an LSP for staff. SBC staff members supported the implementation of the LSP and recognised that it made a valuable contribution to the care of patients with breast cancer. A range of health professionals with differing experiences completed the survey and they all perceived the LSP as an acceptable model of and important for patient care. Staff members' perspectives were also influenced by the positive feedback given to them by patients involved in the programme. This positive feedback may also have increased the likelihood of the LSP being accepted by staff working in the SBC. This study indicates that the LSP is a feasible and acceptable model for SBC staff members and that it was an area of "need" that had not previously been catered for by the health service.

Baseline measures are required to ensure accurate clinical decision making when utilising subsequent measures. Patients whose scores increase by 10 or more units after surgery and yet remain within the normal range may not be identified as having lymphoedema if there is no pre-operative baseline value to compare subsequent measurements against. Pre-operatively, 45.7% of patients in this study had negative bioimpedance scores; therefore, early diagnosis might have been missed in up to 45.7% of this patient cohort if no baseline measure had been taken.

By obtaining pre-operative circumferential measures, changes can more accurately be tracked. The differences in limb circumference following surgery ranged from -4.6 cm to +2.9 cm. Two participants (5.7%) had >2 cm difference limb circumference, which may be indicative of lymphoedema. These results, therefore, reinforce the importance of obtaining pre-operative baseline measures.

It has been shown that individuals with a pre-operative BMI >30 are at a significantly greater risk of developing BCRL compared to those with a BMI <30 (Jammallo et al, 2013). In this study, 42.8% of patients had a BMI >30 and, therefore, are at higher risk of developing BCRL. This highlights the need for an LSP for breast cancer in this population. Weight increases following surgery have also been shown to result in the person having a higher risk of developing BCRL (Jammallo et al, 2013). Education regarding the importance of maintaining a healthy weight is therefore imperative during the surveillance process, as is monitoring of the patient's weight at each subsequent surveillance session.

Limitations and future research

This study only included a small number of participants. It was a pilot using convenience sampling and had limited resources (e.g. staff and funding) available. Despite this, the majority of patients with newly-diagnosed breast cancer seen in the SBC were screened in the LSP. Four patients were not screened in the SBC due to LSP staff absence and the inability of the patients to return for measuring prior to surgery due to the distances required to travel. As distance from the SBC and convenience were found to impact participation, findings from the survey reinforce the need for the LSP to be run in conjunction with the SBC.

Further investigations are warranted following the establishment of the LSP. These could include analysing data gathered from the follow-up surveillance sessions, the effectiveness of involving AHAs in the LSP, and any changes or improvements to the LSP made over time.

Conclusion

This is the first study to evaluate the acceptability and feasibility of a LSP for staff and patients in a regional area. The programme was successfully implemented in a large regional health service. Staff and patients found it to be beneficial and important in the provision of optimal care for patients with breast cancer. Future research to analyse the longer-term outcomes of lymphoedema surveillance and the cost-effectiveness of the LSP would be beneficial.

Table 3. Staff survey results (score range: 0–5), *n*=9.

Statement	Mean score (SD)
I understand why the lymphoedema surveillance programme is being implemented	4.88 (0.33)
The physiotherapy staff have provided a valuable contribution to the care of the breast cancer patients	5.00 (0.00)
The physiotherapy staff have been a beneficial addition to the surgical breast clinic team	4.88 (0.33)
I support the implementation of the lymphoedema surveillance programme	4.88 (0.33)
Overall experience of the lymphoedema surveillance programme in the surgical breast clinic	4.77 (0.44)

Declaration

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