

Patient recall and retention of lymphoedema-linked education knowledge following breast cancer surgery in Australia

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Key words

Breast cancer, education, lymphoedema, recall, retention

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Patients diagnosed with cancer are inundated with information about diagnosis, treatment, and post cancer care. Retaining relevant information is especially important for cancer patients with lymph nodes removed as they are at risk of developing lymphoedema, which is the accumulation of protein rich fluid within their body. Lymphoedema is predominantly caused by damage to the lymphatic system resulting from cancer treatment, including the removal of lymph nodes and radiotherapy to the lymph node groups (Australasian Lymphology Association [ALA], 2021). There is no cure for lymphoedema (Schaverien and Alderich, 2018) but symptoms can be controlled if the disease is detected and treated before significant progression (McLaughlin et al, 2020; Forte et al, 2021; Rafn et al, 2022). Early patient education programmes can lower the risk

Abstract

Introduction: Education on lymphoedema and lymphoedema risk is an essential part of the cancer care package. This study evaluated recall and retention of lymphoedema-linked education knowledge in patients following breast cancer surgery. **Method:** Seventy participants at risk of developing lymphoedema were assigned to a 1:1 or group education programme. Surveys captured self-reported recall of their lymphoedema education and demonstration of upper-limb exercises over 12 months. **Results:** Participant's ability to recall lymphoedema education and associated exercises decreased over time. Recall increased by 12 months but remained suboptimal. Delivery method and lymphoedema risk category were not significant factors affecting participants recall. **Conclusion:** Recall and retention of lymphoedema education was sub-optimal, however, participants with clinical symptoms demonstrated greater knowledge and performance.

of lymphoedema after breast cancer (Hsiao et al, 2014; Lu et al, 2015) and should consist of information on lymphoedema, its risk factors, early signs of development and who to contact for clinical assessment should symptoms occur (Dylke, 2019).

Breast cancer survivors believe lymphoedema education is of high importance (Dorri et al, 2020) but their dissatisfaction, namely inadequate or conflicting information (Kwab et al, 2012; Cal and Bahar, 2016) is also well documented in the literature (Ridner, 2006; Lee et al, 2010; Stout, 2012).

There are also conflicting views about receiving lymphoedema education at time of diagnosis (Ridner, 2006; White et al, 2015; Dorri et al, 2020). Women may not recall or comprehend the arm care and exercise advice they were given because of the shock of cancer diagnosis and surgery (Ardern-Jones et al, 2005; Ostby et al, 2018). Furthermore, distress associated

with the development of lymphoedema may diminish recall of education received prior to onset of the condition (Ridner, 2006; Alcorso and Sherman, 2016).

Breast cancer survivors are at a lifetime risk of developing lymphoedema, a chronic potentially debilitating condition that requires lifelong symptom management (Sherman et al, 2015; Ostby et al, 2018). Greater knowledge, beliefs of lymphoedema controllability and confidence in self management have been identified as important factors that contribute to breast cancer patients adherence to lymphoedema risk reduction and management behaviours (Sherman and Kolmeyer, 2012; Sherman et al, 2015; Ostby et al, 2018; Aydin and Gursoy, 2020). This highlights the necessity to equip patients with adequate knowledge regarding the common signs and symptoms of lymphoedema and where to access local treatment services should symptoms occur.

Provision of lymphoedema education

in the breast cancer population is well supported within the literature. However, there is a lack of evidence on how and when to best provide this education, including the method of delivery and timing of education delivery to optimise patient recall and retention of information. With no standardisation, practice patterns vary (Ostby et al, 2018).

Methods

Study design

A randomised controlled trial was designed to distribute participants into individual (control) or group (intervention) education sessions using a computer-generated randomiser (<http://www.randomizer.org/form/htm>).

Data collection

A questionnaire was specifically designed for this study to compare participant's retention of lymphoedema education between the control and intervention groups. Data were collected at each visit to the clinic (pre- and post-education, and at 3-, 6- and 12-months post-surgery).

The survey allowed self-reporting of participants' knowledge and recall of lymphoedema education provided to them. Participants were also asked to demonstrate range of motion (ROM) exercises for upper-limb post-surgical care, which were observed and scored by the lymphoedema physiotherapist (PT) or occupational therapist (OT). Other relevant medical information was collected from their electronic medical record (iEMR).

Sample size and power calculation

Sample size was calculated on patient's ability to recall two responses to the questionnaire of self-management techniques to reduce the risk of lymphoedema. Confidence level was set at 95% and a power of 80% with a margin of random error (MRE) of 10%. Using the method of Wharrad and Silcocks (2007), sample size was calculated as 61 and 70 participants were recruited to account for a loss of follow of 10%.

Participants and Setting

Patients post-breast cancer surgery between June 2015 and September 2017 were eligible to participate. Participants were referred for routine postoperative lymphoedema education and had no known symptoms of lymphoedema at time of referral.

Inclusion Criteria

- Patients aged 18 years and over
- Patients referred for routine postoperative education following breast cancer surgery and lymph node removal
- Patients whose primary residence was within the Townsville Hospital Health service region
- Patients with no known complications at time of referral.

Exclusion criteria

- Patients demonstrating signs and symptoms of swelling
- Patients unable to attend or failure to attend (FTA) three consecutive allocated sessions
- Patients residing outside of the Townsville Hospital Health service region
- Patients with previous breast cancer surgery
- Had previous lymphoedema clinic input.

Following consent, participants were classified at low or high risk of developing lymphoedema based on the extent of lymph node removal. Sentinel lymph node biopsy (SNBx) was classified as low risk and Axillary Dissection (AD) was classified as high risk. Prior to the commencement of this study, group education was trialled by the research team to ensure acceptability by participants and perceived equivalence to individual education.

Intervention (group education)

Group education (intervention group) was presented by both the lymphoedema OT and PT (ALA accredited). Only the initial education session was in group format with numbers varying between 2–6 participants and subsequent education presented individually. Families and carers were encouraged to attend. Follow-up was scheduled at 3-, 6- and 12-months postoperatively as per the usual care.

Control (Individual education)

Control participants received individual education (1:1) with either lymphoedema therapist (OT or PT). Follow-up was scheduled at 3-, 6- and 12-months postoperatively as per the usual care.

Study protocol

Education sessions were scheduled approximately 3–4 weeks post-surgery. Variations in the timing of education occurred due to timeliness of referrals and patient or therapist availability. Eligible participants were contacted by phone to determine

interest in participation. If interested, potential participants were mailed an appointment letter, participant information sheet and consent form.

Education included information on lymphoedema, the lymphatic system, risk factors for lymphoedema, signs and symptoms of lymphoedema, and risk minimisation strategies. Upper-limb range of motion exercises and scar massage techniques were also taught. All techniques were initially demonstrated by the therapist, then participants practiced under observation during the sessions.

Education sessions were didactic using a PowerPoint presentation and accompanying script to ensure consistent information was delivered. Participants were provided with written information and instruction sheets for all educational content. Both control and intervention sessions were 1 hour in duration. Assessment of participants followed immediately after the education session. Additional appointments were scheduled as deemed clinically necessary if participants from either group presented with or reported complications. All participants were provided relevant handouts and brochures.

Statistical analysis

Frequency and descriptive analyses were performed between groups of interest for relevant variables. As we split groups into high and low risk before randomising, the data are presented as: overall control versus overall Intervention; control versus intervention of low risk participants; and control versus intervention of high-risk participants. Difference in mean or median tests or Chi-square analyses were run to examine statistical significance between groups where appropriate, with P values of <0.05 considered statistically significant. All analyses were undertaken using SPSS v25.

Results

A total of 69 females and one male were recruited to the study. The mean (SD) age of participants was 57.4 (11.2) years with 35 participants deemed low risk and 35 high risk based on lymph node status. Baseline demographics presented by risk category and education type are shown in *Table 1*. Low-risk participants have a similar demographic profile across the control and intervention groups. Similar patterns are found in the high-risk group, with control patients having lower median days since

referral to initial presentation than the Intervention group. High-risk participants had a lower median number of days since referral to initial presentation compared to low-risk participants.

An attrition rate of 30% was observed with 48 participants completing the study (Figure 1). Reasons for withdrawing included: personal/health reasons (n=3); felt they no longer required input (n=8); failed to attend (n=6); relocated (n=3) or treated elsewhere (n=2). No significant differences in demographic information were found between those with complete data over the 12-months, and those lost to attrition (P values >0.05). Due to low study numbers, all available data prior to participants leaving the study were used in the statistical analysis.

Participants experiencing postoperative complications or symptoms of lymphoedema at baseline required additional appointments. However, there was no significant correlation between total number of symptoms at baseline and number of extra visits required by participants between 3-6 months and 6-12 months (P >0.05) nor any significant difference in number of extra appointments required between risk groups.

Symptoms

There was no difference in symptoms of lymphoedema between the control and intervention groups at baseline. As expected, acute postoperative symptoms decreased over time and the incidence of swelling, especially in the high-risk participants, increased (Table 2). This is likely to indicate development of lymphoedema in these patients.

Patient reported confidence

High levels of confidence and recall was reported by participants immediately post education. Participants agreed (29%) or strongly agreed (71%) they were confident to perform their prescribed postoperative exercises. Similarly, all agreed (41%) or strongly agreed (59%) that they were confident in recalling possible signs and symptoms of lymphoedema.

Clinical signs and symptoms of Lymphoedema

Participants were educated on the six common symptoms of lymphoedema (swelling, ache, heaviness, tightness, tiredness and fullness). Participants on average identified 1.1(0.8) out of the six symptoms prior to education which increased to 2.9 (1.1) immediately

Table 1: Patient demographics.

		Low risk (n=35)			High risk (n=35)		
		1:1 (n=19)	Group (n=16)	Total	1:1 (n=24)	Group (n=11)	Total
Side	Right	9 (47)	9 (56)	18 (51)	15 (63)	7 (64)	22 (63)
	Left	10 (53)	6 (38)	15 (46)	8 (33)	4 (36)	12 (34)
	Bilateral	0	1 (6)	1 (3)	1 (4)	0	1 (3)
Type of surgery	WLE	12 (63)	10 (63)	22 (63)	7 (29)	4 (36)	11 (31)
	TM	7 (37)	6 (37)	13 (37)	17 (71)	7 (64)	24 (69)
Having Chemo	Yes	18 (95)	15 (94)	33 (94)	15 (63)	8 (73)	23 (66)
Having XRT	Yes	1 (5)	1 (6)	2 (6)	24 (100)	9 (82)	33 (94)
Mean (SD) age		58.2 (10.8)	56.7 (12.1)	57.5 (11.3)	58 (11.6)	55.9 (11.3)	57.3 (11.4)
Median (IQR) number of positive nodes		0 (0-0)	0 (0-1)	0 (0-0)	2.5 (1-6)	3 (1-4)	3 (1-5)
Median (IQR) number of lymph nodes		10 (7-13)	5 (2-9)	8 (6-12)	14 (7-20)	3 (1-7)	7 (3-15)
Median (IQR) days since referral to initial presentation		28 (25-36)	30 (22-48)	29 (24-37)	22.5 (20-28)	33 (21-36)	24 (20-30)

WLE- wide local excision, TM- total mastectomy, XRT – radiation

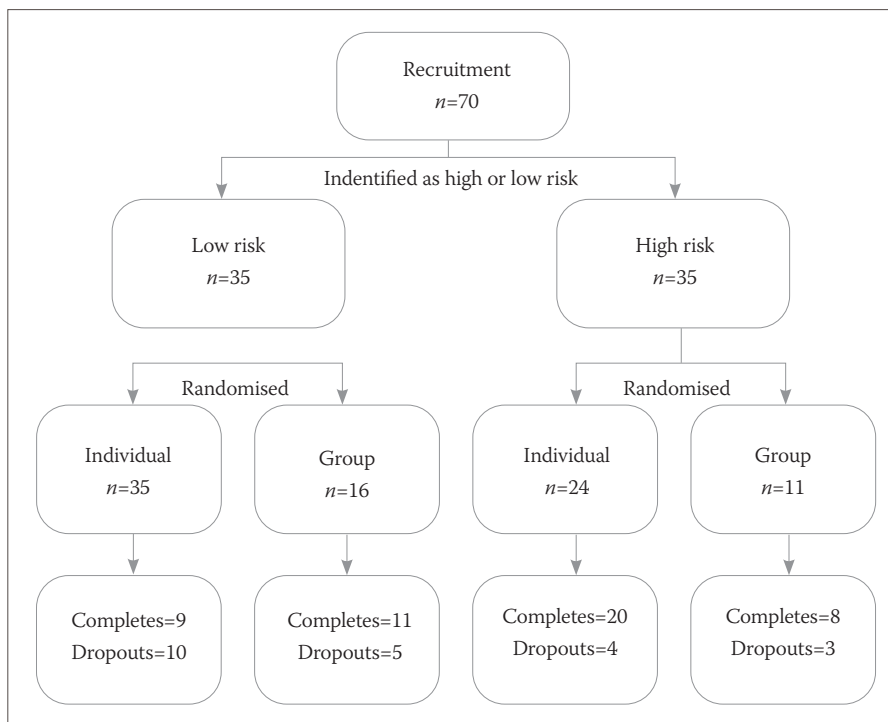


figure 1: Flow diagram for the study.

post-education. By 3 months, recollection decreased to 1.8 (1), then slightly increased to 2.1 (0.9) by 12 months. Swelling was the most frequently recalled symptom (>81%)

followed by heaviness (<56%), aching (<44%) and tightness (<47%).

At each session, participants were asked to recall any symptoms that may prompt them to

contact the clinic for an earlier appointment. Most (87%) reported they would contact their therapist if they noticed swelling in their at-risk limb. Of the other symptoms promoting contact included pain (37%), 18% heaviness and 13% aching. There were no significant differences between risk or group allocation.

Risk reduction strategies

The ability to recall lymphoedema risk reduction strategies increased slightly over time for all groups (Table 3). The two main strategies recalled were exercise and manual lymphatic drainage (MLD). MLD was discussed during education as a technique to utilise if participants developed symptoms of lymphoedema but not taught as a method of risk reduction. Risk reduction strategies recalled by participants included maintaining a healthy weight and avoiding sunburn. There was no difference between intervention and control groups in participant's recollection of lymphoedema risk reduction strategies. Participants could indicate more risk reduction practices when presented with a comprehensive 'tick and flick' list than by recall alone.

Postoperative exercises

Participants were assessed on the number of postoperative breast cancer upper limb exercises they could demonstrate correctly. Out of a total eight exercises taught, participants could demonstrate a mean of 4.88 (1.98), 3.41 (2.47), 3.43(2.30) and 3.63 (2.8) immediately post, and 3, 6 and 12 months after education, respectively. Their post-education recollection was significantly higher than all other time points ($P < 0.01$). Intervention participants showed better demonstration of exercises, but this improvement did not achieve significance (Table 4). There was no difference in risk category or symptoms present between the groups (P values > 0.05).

Discussion

Lymphoedema education is a core component in the care of patients with breast cancer. This study assessed the impact of introducing an intervention (group education) and participants' recollection of the education. Previously, education was delivered individually and the rationale for introducing group education was to increase capacity in the lymphoedema clinic. Authors also wanted

Table 2: Number of patients with symptoms over time.

Time	Risk	<i>n</i> (%) of participants with symptom			
		Scarring	Cording	Swelling	Seroma
Pre	Low (<i>n</i> =35)	9	17	9	11
	High (<i>n</i> =35)	16	26	9	15
3 months	Low (<i>n</i> =30)	<5	<5	6	0
	High (<i>n</i> =33)	9	20	10	<5
6 months	Low (<i>n</i> =27)	<5	<5	5	0
	High (<i>n</i> =30)	6	11	16	<5
12 months	Low (<i>n</i> =21)	0	<5	<5	0
	High (<i>n</i> =28)	5	6	17	0

WLE- wide local excision, TM- total mastectomy, XRT – radiation

Table 3: Mean (SD) number of risk reduction strategies identified at each time point.

	Low risk		High risk	
	1:1	Group	1:1	Group
Pre	1.7 (1.5)	1.1 (0.8)	2 (1.4)	1.7 (1.1)
Post	2.8 (0.8)	2.5 (0.9)	3 (1.1)	2.7 (1)
3 months	2.4 (1)	3 (0.8)	2.8 (1)	2.5 (1.1)
6 months	2.9 (1.2)	3.2 (0.9)	3.1 (1.1)	2.2 (1.4)
12 months	3.1 (1)	3.8 (1.7)	3.2 (1.2)	2.6 (0.7)

Table 4: Participants ability to demonstrate postoperative exercises.

	Low risk		High risk	
	1:1	Group	1:1	Group
Post (<i>n</i> =70)	4.4 (2.1)	3.8 (2.4)	5.1 (1.8)	4.5 (1.2)
3 months <i>n</i> =63	3.2 (2.3)	2.5 (2.6)	3.8 (2.4)	2.3 (1.9)
6 months <i>n</i> =56	2.7 (2.6)	2.4 (2)	3.8 (2.3)	3.6 (2.1)
12 months <i>n</i> =48	4.8 (3)	1.9 (2.8)	4.1 (2.7)	3.4 (2)

to determine if individual lymphoedema risk of participants influenced their education retention and adherence.

Overall, the results show high attrition and low recollection of lymphoedema education. Participants' self-reported confidence to recollect the education and perform exercises correctly was at odds with their actual ability, similarly to Krzywonos et al (2014). This divergence may be attributable to the complexity of educational content, shock of cancer diagnosis (Ostby et al, 2018), timing of education (Ridner, 2006; White et al, 2015; Dorri et al, 2020), method of delivery or socially desirable responses (SDR) (Blair and Coyle, 2005, Cossette et al, 2005). The high attrition of participants continuing the education sessions, especially those at low risk may suggest this group feel

lymphoedema is of a low priority. This is a concern as ongoing education is vital to heighten the patients' awareness of potential late effects from treatment and to promote a proactive approach to their diagnosis and treatment in addition to reinforcing health promoting behaviours (Stout et al, 2012).

Previous studies indicate patients are dissatisfied with pre- and post-surgery education (Ridner, 2006; White et al, 2015; Dorri et al, 2020). Many of these studies state patients report not being told of the risk of developing lymphoedema or of risk reduction strategies before or after breast cancer treatment (Radina et al, 2004). Results from the current study show that despite reiterative education, participant's had poor recall of risk reduction strategies suggesting an inability

to retain information at this stressful and disruptive time in their lives. Research also suggests that even when well informed, they do not necessarily adhere to recommended self management regimens and that awareness is highly variable (Sherman and Koelmeyer, 2011; Kwan et al, 2012; Sherman et al, 2015).

Participant's recall of information and demonstration of exercises improved slightly by 12 months. Similar to Bani et al (2007), the development of clinical symptoms may be a motivator to retain or relearn information. High-risk participants scored better than low risk as did those allocated to Control compared to the Intervention education. High-risk participants had more appointments with the therapists due to clinical need suggesting the reiterative education may have improved knowledge retention. Sherman and Koelmeyer (2011) similarly report that booster education sessions can benefit longer-term retention and adherence to recommended behaviours.

The incidence of swelling increased by 15% over the course of the study, potentially indicating lymphoedema, a result comparable to other studies (DiSipio et al, 2013). However, no differentiation between postoperative or acute radiation induced oedema and lymphoedema was made, therefore, the development of lymphoedema in our cohort may have been higher.

Group sessions were proposed as an efficient use of therapist time and may provide peer support among the participants (Sharif et al, 2009; Tehrani et al, 2011). The observed low attendance rates at the monthly group sessions were primarily due to clashes with other cancer-related medical appointments and the commencement of adjuvant cancer treatments. Participation rates may have increased if the frequency of group sessions increased. However, the potential time saving from holding group education sessions was negated by the increased administrative burden to an untenable level and was discontinued following the study.

Several limitations were identified in this study. Firstly, no blinding of therapists or participants could be performed due to the nature of the intervention. Secondly, the high attrition, especially of the low-risk

cohort, meant numbers in each group were insufficient to demonstrate power of analysis and some data could not be reported. Finally, recruitment time for the high-risk group was slow, meaning many entered the study several months after completion of low-risk patient recruitment.

Overall, this study showed that recall and retention of lymphoedema education is suboptimal. Risk category and education type (group v 1:1) do not appear to be significant factors. The clinical impact of this study has resulted in a change in practice within the lymphoedema clinic by reducing the amount of education provided per session but maintaining frequency of iteration and abandoning group education sessions.

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