

ORIGINAL ARTICLE

Yoga, breast cancer-related lymphoedema and well-being: A descriptive report of women's participation in a clinical trial

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Aims and objectives: To describe the experiences of women taking part in a yoga intervention trial for breast cancer-related lymphoedema.

Background: Around 20% of women will experience lymphoedema as a consequence of treatment for breast cancer. Specialist lymphoedema clearing, along with self-management, remains the mainstay of therapy. Yoga, an increasingly popular complementary therapeutic practice, may provide another tool to augment self-management.

Design: A qualitative, descriptive design.

Methods: Interviews were conducted with 15 women with stage one breast cancer-related lymphoedema who had completed an 8-week yoga intervention trial. The intervention consisted of a weekly teacher-led 1.5-hr yoga class and a daily home practice using a 45-min DVD. Interviews were audio-taped and transcribed. These data were then analysed using an iterative-thematic approach.

Results: Participants reported improved well-being, increased awareness of their physical body as well as improved physical, mental and social functioning. They gained from being part of the yoga group that also provided a forum for them to share their experiences. Nine women felt empowered to describe their yoga participation as a transformative journey through illness.

Conclusion: When safe to do so, the holistic practice of yoga may augment and provide additional benefit to current self-management and treatment practices for women with breast cancer-related lymphoedema.

Relevance to clinical practice: Patients with breast cancer-related lymphoedema may seek advice and guidance from nurses and other healthcare professionals on a range of complementary therapies to help relieve symptoms and promote recovery. Patients who choose to augment their treatment of breast cancer-related lymphoedema by practicing yoga should be carefully assessed, be taught an appropriate technique by a qualified yoga teacher/therapist and its impact monitored by their yoga teacher/therapist, breast care nurse, lymphoedema therapist or treating clinician.

KEYWORDS

breast cancer, exercise, journey, lymphoedema, nursing, well-being, women, yoga

1 | INTRODUCTION

While improvements to surgery and radiotherapy continue to provide better clinical outcomes for breast cancer, at least 20% of women treated will be diagnosed with breast cancer-related lymphoedema (BCRL; NBOCC, 2008). This condition affects the physical, mental and social domains of their lives (Chun & O'Connor, 2011) and requires lifelong treatment, including self-management (Lymphoedema Framework, 2006). A recent systematic review and meta-analysis on the effects of exercise for those with cancer-related lymphoedema concluded that progressive, regular exercise did not worsen lymphoedema or related symptoms (Singh, DiSipio, Peake, & Hayes, 2016) women are searching for and using complementary therapies, including yoga, alongside usual treatment and daily self-management regimes, to alleviate and control symptoms (Finnane, Liu, Battistutta, Janda, & Hayes, 2011; Girgis, Stacey, Lee, Black, & Kilbreath, 2011).

Nurses play a key role in caring for women diagnosed with breast cancer. Breast care nurses provide ongoing counselling, information and support relating to all aspects of breast care and, through collaboration and liaison with others, enable continuity of care to be provided throughout treatment and the rehabilitative process. An understanding of how women with BCRL engage with and experience yoga will contribute to more effective monitoring, safe referral and management of what can be an extremely debilitating, lifelong condition.

2 | BACKGROUND

Upper body impairment from BCRL can lead to difficulty with many activities of daily living, a changed view of self, reduced physical activity and lower quality of life (QOL; Chun & O'Connor, 2011; Fu & Rosedale, 2009; Hayes, Janda, Cornish, Battistutta, & Newman, 2008; Ridner, 2005; Thomas, Quinlan, Kowalski, Spriggs, & Hamoline, 2014). Women with BCRL have greater medical needs which can incur additional costs for treatment and support (Shih et al., 2009). They report feeling isolated, marginalised and abandoned (Ridner, 2005). They complain that there is often a lack of understanding of lymphoedema and appropriate referral to specialist treatment (Fu & Rosedale, 2009; Girgis et al., 2011). This is worse for those living in rural and more isolated locations (Greenslade & House, 2006; Thomas et al., 2014).

The aim of yoga is to provide tools that enable an individual to holistically improve the functioning of their body, mind and spirit (Saraswati, 1996) irrespective of their condition and environment. Positive outcomes have been reported from integrated yoga interventions in various populations (Chen et al., 2008), including women recovering from breast cancer treatment (Harder, Parlour, & Jenkins, 2012). Further, several small studies have concluded that yoga may benefit women with BCRL.

Two randomised controlled trials (RCTs) for women with BCRL have reported outcomes. The first ($n = 19$) reported a trend to

What does this paper contribute to the wider global clinical community?

- Complementary therapies are being used by women in the self-management of breast cancer-related lymphoedema (BCRL). Yoga which adheres to safe guidelines for lymphoedema management may have a role.
- Participation in yoga, as a holistic practice, may offer women with BCRL some physical and psychosocial benefits with appropriate teaching and support.

improved tissue density and lymphoedema status for those who continued with yoga 6 months after a 4-week trial (Douglass, Immink, Piller, & Ullah, 2012). The second ($n = 28$) consisted of an 8-week yoga intervention with a home-practice DVD reported reduced tissue density of the affected upper arm, an improvement on the *symptoms* subscale of the Lymphoedema Quality of Life Tool (Loudon, Barnett, Piller, Immink, & Williams, 2014) as well as increased pelvic stability and shoulder strength (Loudon et al., 2016). A single group pre/post-test pilot trial, with a convenience sample of six women with BCRL, reported decreased arm volume of lymphoedema following an 8-week yoga intervention programme (Fisher et al., 2014). Another single group study ($n = 8$), designed to trial a yoga protocol and compression for BCRL, reported reduced lymphoedema volume and improvement in range of movement (Narahari, Aggithaya, Therne, Bose, & Ryan, 2016).

The rise in the popularity of yoga has led to an increased focus on specialised therapeutic yoga, with one in five Australian yoga practitioners attending for medical reasons (Penman, Cohen, Stevens, & Jackson, 2012). Standards for yoga therapists now exist in Australasia (AAYT, 2015) and internationally (IAYT, 2016). As women with BCRL are attending yoga classes (Finnane et al., 2011; Girgis et al., 2011), it is important that their experiences be explored to better inform and shape these practices. Studies that principally apply empirical measures of health outcomes should be complemented by richer and more descriptive accounts of participation and more subjective assessments of health benefits. Our literature search located only one published qualitative study for women with impairment from breast cancer treatment ($n = 13$) which included some women who had lymphoedema (Thomas et al., 2014). For this reason, 15 women with BCRL who had taken part in a RCT were interviewed at the completion of the trial. Our aim was to understand their experience of participation in the trial and their views of the yoga intervention.

3 | METHODS

The study was a RCT conducted in Tasmania, Australia, with data collected using a variety of methods. The Human Research Ethics Committee (Tasmania) Network approved the study and the trial

registered with the Australian New Zealand Clinical Trials Registry (ACTRN No. 12611000202965). The full study protocol has been described elsewhere (Loudon et al., 2012) as have the results of the quantitative measures (Loudon et al., 2014, 2016).

Women aged over 18 with no concurrent health problem who had stage one BCRL (Lymphoedema Framework, 2006), confirmed by a professional lymphoedema therapist, were recruited through advertisement. Prior to the study, they were required to have completed all breast cancer treatment (apart from hormone treatment) for at least 6 months and were advised to continue with their usual treatment plan during the trial and to seek advice from their lymphoedema therapist or doctor should any sign or symptom of infection or exacerbation of lymphoedema occur. Of the 59 women who responded to advertising, 13 did not meet the inclusion criteria and 18 declined inclusion, due to the location ($n = 9$) or the dates ($n = 3$) and times ($n = 3$) of the proposed classes. The remaining 28 participants were randomly allocated to a yoga intervention ($n = 15$) or a usual care ($n = 13$) control group by a person independent of the trial using a computer-generated random number system on a 1:1 allocation ratio. Those allocated to the control group were wait-listed and received the intervention after all measurements had been finalised.

The 8-week yoga intervention was based on Satyananda Yoga[®] (Saraswati, 1996) and comprised breathing, gentle repetitions of adapted physical movements with individual modifications, followed by rests, meditation and relaxation practices in a sequence designed to progressively empty lymph from proximal to distal, reteach symmetry of movement patterns and improve biomechanical control of shoulder actions (Table 1). The yoga followed recommendations for physical exercise for those with lymphoedema, such as slow warm-up and cool-down (Lymphoedema Framework, 2006). Women attended a weekly 1.5-hr class and used a 45-min DVD for daily home practice. The DVD was a modified version of the full class by including fewer of the class postures, a shortened introductory breathing session and final relaxation. As in the class, it included adaptations to accommodate women with different needs. For example, a chair-seated version for every posture was demonstrated and staged instructions provided. The content of the DVD was taught at the first two class sessions to ensure participants understood the instructions and performed each action safely and correctly within their capability.

In addition to the application of validated instruments and measures to assess physical changes and symptoms, subjective data were also sought. At the completion of the intervention, face-to-face audio-taped interviews were conducted with each of the 15 women from the yoga intervention group to record their subjective experiences of participation. These were held in a quiet, private room and conducted by an experienced interviewer independent of the research team. The questions were open-ended and designed to help initiate conversation about the women's experience of the trial; for example, "How has the yoga been for you?" "Can you tell me about how the yoga has helped or been difficult for you?" Relevant comments were explored further by

TABLE 1 Outline of yoga class and DVD based on adapted Satyananda Yoga[™]

Activity	Class	DVD
1. Welcome and questions about home practice	5 min	
2. Settling and breathing	10 min	5 min
<ul style="list-style-type: none"> • Body awareness (<i>Kaya Sthairyam</i>^a) • Mental awareness • Three-part breathing • Full yoga breath 		
3. Practices	45 min	25 min
<ul style="list-style-type: none"> • Slow and steady with breath awareness • Each posture repeated 5–7 times. Based on: <ul style="list-style-type: none"> ○ Clearing lymph from proximal, then from distal ○ Creating alternative pathways ○ Swiping actions to take lymph to working lymph nodes ○ Individual variations, if required 		
4. Pranayama and meditation	15 min	5 min
<ul style="list-style-type: none"> • Alternate nostril breathing (<i>Nadi Shodan</i>) • Mindfulness—witnessing (<i>Antar Mouna</i> level 1: weeks 1–4, and level 2: weeks 4–8) • Meditation—candle gazing (<i>Tratak</i>—weeks 4–8) 		
5. Relaxation	15 min	10 min
<ul style="list-style-type: none"> • <i>Yoga Nidra</i> (systematised by Swami Satyananda). 		
6. Discussion	5 min after class	

^aItalicised words are Sanskrit.

prompting (Patton, 2002); for example, "So you said your posture improved. Can you tell me how exactly?" Each interview lasted around 20 min.

The interview audio-recordings were listened to several times to gain a general understanding and then transcribed verbatim into Word documents. Specific features, such as moments of laughter, hesitation, silence and emphasis, were noted in the transcripts (Silverman, 2007). Data analysis was by an iterative-thematic approach. Two researchers, working independently, marked in the margins of the text a code word or phrase representing ideas expressed in the interviews. This emphasis on text, without any imputed meaning from the researchers, was regarded as important to validation (Charmaz, 2006), as was the simultaneous analysis by different researchers (Cavanagh, 1997). Focussing on these codes and their frequency, the researchers then grouped the data into topics and subthemes and then aggregated these into major themes (Graneheim & Lundman, 2004). Throughout this process, the two researchers met regularly to test individual interpretations, resolve discrepancies and verify data sorting and coding procedures (Downe-Wamboldt, 1992; Graneheim & Lundman, 2004). Finally, illustrative textual statements were identified and listed under each topic and theme to confirm consistency (Silverman, 2007). These were subsequently checked by another member of the research team.

4 | RESULTS

The characteristics of participants are listed in Table 2. Attendance at each class (97%) and self-reported compliance with the home-practice DVD (86%) were high throughout the trial. Only two of the 15 women had previously practised yoga, and this was some years prior to being diagnosed with breast cancer and secondary arm lymphoedema. A summary of the major themes and subthemes that were generated from the data analysis is provided in Table 3. Each theme is described more fully in the following.

4.1 | Well-being

All participants spoke about the impact they felt the yoga had on their well-being irrespective of length of time of diagnosis. For example, a woman who had lived with lymphoedema for 20 years stated:

Something in my overall sense of wellbeing has taken place in this past couple of months, as much as anything I can identify physically. (#1)

Similarly, a woman with a more recent diagnosis commented:

I think that in terms of my general wellbeing, yoga has contributed to a gradual road to recovery . . . on a lot of levels and that's sort of what I like. It's not just helped me physically; it's helped me physically, mentally, emotionally, you know, a little bit on all levels, which is really nice. (#7)

Another stated: my general wellbeing has benefitted very, very much. (#11)

4.2 | Greater awareness of body and improved physical functioning

All participants made reference to having a greater awareness of their body and how they moved:

TABLE 2 Characteristics of participants and types of treatment (n = 15)

Characteristic	Mean ± Standard deviation	Range
Age (years)	55.2 ± 8.7	36–66
BMI (kg/m ²)	29.5 ± 4.4	21–37
Lymphoedema (years)	5.0 ± 5.2	0.5–20
Diagnosis postsurgery (years)	1.2 ± 1.4	0.3–3.5
Number of nodes removed	13.7 ± 8.0	5–30
Breast cancer treatment received	Frequency	Percentage
Mastectomy	10	67
Axillary dissection	13	87
Radiotherapy	12	80
Chemotherapy	10	67

TABLE 3 Themes and subthemes (n = 15)

Theme	Sub-theme (n)
Well-being	Overall well-being (15)
Greater awareness of body and improved physical functioning	Awareness of the physical body and movement (15)
	Symptoms, for example, pain, heaviness (11)
	Arm and core strength and shoulder range of motion (10)
	Posture (8)
	Flexibility, suppleness (4)
Improved mental health and social functioning	Benefits of group support (15)
	Altruism (13)
	Greater mental awareness (12)
	Time for self, regaining control (12)
	Improved relationships (11)
	Sleep patterns (9)
	Equanimity and calmness (7)
	Optimism and hope (6)
	Self-discipline (4)
The breast cancer journey	The experience of breast cancer (15)
	Transformative journey through illness (9)

I've found the yoga has made me very, very much more aware of how everything actually operates. And so, instead of just doing something, the exercises that we've been given, I actually have put some thought into what I'm doing and how I'm doing it, rather than just barging in with no thought at all. (#2) and:

I'm now more conscious of keeping my body more upright and learning to move in a relaxed manner and by having an awareness of what's happening with my body trying to maintain a healthy way of being. (#1)

Eleven women reported improvements to the affected area and in the physical symptoms associated with lymphoedema, such as pain and heaviness:

My underarm area, which a build-up of fluid usually makes tight and sore, has been a lot more flexible. (#8) My breast is not swollen in the way it used to be. There's a lot less fluid there, because I was retaining a lot of fluid. Where the scar is on my breast – because of all the yoga and the DVD I am doing at home – my scar is a lot softer. (#2) When you go through the yoga, if you can just lie there at the end, there's no heaviness, no pain, the lightness is just absolutely wonderful. . . (#12)

Women's comments revealed their new knowledge about movement, releasing face tension, being aware of their centre of gravity and consciously relaxing. For example, two women commented that they now knew when they were overusing their affected arm, while another realised that she ignored her affected arm and did everything with her nonaffected arm. Further, three participants stated the necessity for greater personal vigilance, whether it be "doing the DVD in a slow and steady way when the humidity makes my arm heavy" (#8) or keeping "my *sankalpa*, my promise to myself, getting rid of this extra weight because that's what my lymphoedema needs" (#4) or simply "looking after myself, particularly my arm, a lot more." (#3)

Further, the participants reported increased mobility and flexibility, greater arm and core strength and sustained improvements around the affected arm and shoulder area. Some women reported that they were now able to undertake activities they had previously been unable to perform:

I can now open my garage door for the first time in 20 years . . . I can lift up and hold my grandchildren. (#10)

When I bend, I can actually touch the floor now, which I haven't been able to do for a long time. (#2)

Moreover, eight women noted a more correct posture, perhaps due to their new-found physical awareness. "After doing the yoga," observed one participant, "my back would be a bit straighter, my shoulders in the right position and I felt as though I was walking taller" (#3). Another stated:

I now have to consciously ensure that my weight is spread evenly when standing, knees slightly bent, pressure evenly on all points of the foot, especially the heel; I normally tend to stand with knees quite stiff when not moving, so this has been good for me. (#1)

4.3 | Improved mental health and social functioning

Participants reported improved mental health and social functioning. Attending the yoga class created a strong sense of connection among the 15 women. They spoke positively about feeling safe during the classes and about the trust developed with the other participants:

And just the whole group, we just seemed to gel so well that there were times when we ran late because people were opening up to each other with their stories. And that to me was really quite. . . it was lovely to think that other people would share what they experienced because sometimes you tend to shut off. I know back in my early days, when I first was diagnosed, I wouldn't share with anybody. (#10)

Many appreciated listening to and learning from the often inspiring contributions of other participants, which created a feeling of

"optimism and hope." (#7) For some participants, this outcome was unexpected, as they had previously chosen not to participate in a self-help or support group:

I didn't expect to feel any similarities [with other members of the group] but I know now that sharing with a group of women in that way had a very big impact on me. (#15)

A sense of altruism was expressed. Participants spoke with enthusiasm about their commitment to help others with lymphoedema by participating in the trial:

I think it's worthwhile, in a wholesome way, to know that you've helped, potentially helped, to make some changes in the treatment or management of lymphoedema. So that knowing you're part of something bigger is, for me, a lovely feeling. (#9)

This altruism also helped create the strong compliance observed for this trial:

My commitment to helping others actually helped me to be more focussed and more committed to doing the yoga. (#14)

Twelve participants report a heightened mental awareness:

Mentally I've been fascinated because I never realised I had such a disorganised brain. I always thought I was a person who was able to focus and achieve to do things, but I've just discovered I've got a brain that drifts off like a butterfly and it cannot be brought to focus and hold a focus for very long. (#2)

One woman mentioned her new-found ability to consciously shut out unwanted thoughts; another her recognition that stress levels were mounting; a third her desire to find time for herself without feeling guilty: "I have stopped rushing home every evening after work. I actually feel ok to go somewhere else now. I have gone out to dinner and I've felt good." (#3)

A number emphasised that they were able to focus better, think more lucidly and change negative habits: "I've actually been able to plan my days better, be more precise, not um-and-ah so much about what I need to do and what has to be done." (#4) and for another, "I'm just going with the moment, it just makes me feel so much more at ease about everything; it just really flows into all areas of my life." (#3)

All this led to greater positivity: "There just seems to be a flow-on effect of positiveness" (#10), a new buoyancy: "I now look forward to things and I'm a lot more motivated" (#11), greater self-confidence: "It just makes me feel more confident about the future" (#14) and reduced self-criticism: "Now I say to myself, don't be so

self-critical, just get on with it, don't be stressed by it" (#15) and with that, less concern about body image: "I feel like my convoluted arm doesn't really matter" (#13). Along with reduced anxiety, "the necessity to focus on the yoga has helped me to clear away anxiety and daily pressure" (#15), was a commonly reported sense of calmness:

Being calm carries over into a feeling of contentment. And just being happy with life the way it is. You don't always have to look at the bigger picture and think: 'oh, the grass is greener on the other side' and all that sort of thing. You just accept what you've got and be grateful. (#6)

Calmness was also related to improved sleep, as one woman said, "I've noticed that I've drifted off quite well by not worrying, not reviewing the day as it was, or thinking of what I have to do tomorrow." (#4) Seven others reported improved sleep patterns:

Since I've been doing the yoga, I find that I'll go four or five nights in a row before I hit a bad one, instead of being 'one up, one down' as before. (#2)

and

When I finish the practices, I go to bed and I sleep right through. I don't even have to get up to use the bathroom or anything. (#11)

Another attributed her improved sleep to the reduction of symptoms associated with lymphoedema, '...the things that keep me awake – blocked nerves, tingling, nerve impingement of my good arm – it was good that those nights when I did the yoga late, I could sleep better.' (#6)

Participants recognised that the daily yoga gave them an opportunity to appreciate "time for self." One commented:

It's made me give time to myself for that hour or so that I've been doing the yoga each day. And I think that's probably really important, that we should all just, every now and then... there should be time-out. So, it's made me experience that time-out for myself. Having time-out for yourself is something that is very, very important. (#7)

Increased self-confidence enabled participants to use the yoga practices to help themselves. Breathing and meditation, for example, allowed them to prepare for the day ahead in a more focussed way and to reduce the interference from negative thoughts and emotions. Some used the yoga DVD in times of stress:

The last three days I've been typing an assignment and I felt like I was going bonkers sitting in front of the computer. I kept getting up and walking around; and, this afternoon, I thought 'I've had three days of this, I'm irritated,' and then I thought 'I'm going to do my yoga.' I

don't usually do it till five but I thought 'No, I'm going to do it today at three' and it was just like 'Ah, that's what I needed to bring balance back into my life.' (#9)

Participants provided examples of increased sociability, benevolence and confidence in expressing themselves with greater frankness:

I'm more relaxed about sharing. (#10)

It has helped me to find all the good things in people. (#6)

I just say things if I want to say them now, whereas before I would get all churned up. (#12)

Four women reported that family members had noticed their greater equanimity. Some identified changes in the relationships they had, consciously stopped habitual negative reactions and became more tolerant and accepting:

I have a better relationship with my husband, because I used to be very snappy, very, and any little thing he said to me, we fought...now I stop before I snap and we don't fight. (#11)

My husband for the last two years has suffered chronic depression. I realized that me being more accepting and relaxed has helped me a great deal... to cope with him. (#10)

I'm much less volatile with my girls who really know how to push my button. (#4)

4.4 | The breast cancer journey

All participants referred to some aspect of the legacy of breast cancer. The presence of lymphoedema was a constant reminder of their illness experience and was never too far from their consciousness. One woman, who had undergone surgery 10 years previously, commented:

There are still days when it's quite nice to get under the doona and stay there and howl a bit. And I would encourage other women to do that. You do have to let go. And just feel miserable and angry. (#8)

However, participants also spoke about renewed control over their own health and about the confidence that had now replaced negativity and fear (of the cancer returning). One participant expressed it as follows:

The yoga has made me think more outwardly and stop worrying about every little medical thing and every little aspect of my body that's affected by cancer. (#13)

Another woman, who for the entire duration of her breast cancer and lymphoedema treatments had been “buffeted around,” welcomed this opportunity to take charge of her life.

Participants voiced their frustration with the lack of postsurgery support and information about lymphoedema from medical staff. They talked about how wonderful it would be if another self-management option could be found that could reduce/control lymphoedema and improve their QOL:

Since medical authorities underestimate the value of complementary and alternative therapies, more trials of this nature would make women with lymphoedema more aware of alternative self-management options. (#15)

Nine participants reported that they found participation in the yoga trial transformative. One participant reported that the experience had “a profound impact on my sense of self” (#2). These experiences were coded as “Journeys” and represented significant life changes. The names given to their *Journeys* identified the key change reported by each woman; for example, *Journey towards my former self*, *My second journey*, *My journey to self-knowledge*, *Back in control*, *Increasing my confidence* and *My journey to holistic health*. One participant described herself as “very, very depressed, very low, very run-down” prior to the trial whereas at the conclusion she stated that she felt:

... calmer, more confident and more relaxed... I look forward to doing things... I'm a lot more motivated... I have made gradual but continuous progress over the two months, bringing me back to the woman I was. I don't say 100% but I am almost 100%. (#11: Journey towards my Former Self)

Three of the “*Journeys*” are illustrated as follows.

For one participant, the possibility of “maybe down the track being able to support or help somebody else” was an important motivation to take part in the trial even though it meant revisiting parts of a journey that she had made 20 years earlier when first diagnosed with breast cancer. It was also the amount of time that she had had lymphoedema. In talking about her second journey, this participant stated:

I loved the yoga classes, I've been happy to share, instead of shutting myself off, as I did before, when I didn't share with anybody. I told nobody. I continued to work. My boss knew. And so, I'd go to work in the morning and then I'd go and have my radiation treatment in the afternoon, go home, go to bed, get up and go to work in the morning. (#10)

Making the decision to participate evoked many strong memories from the past although she concluded that “Being part of that group

of women was a really powerful experience for me.” and one that “has brought me emotional and physical benefits, in all areas of my life.” (#10: *My second journey*)

Another journey was described by a 65-year-old participant who, prior to the trial, reported that she was always tired, lacked energy, felt withdrawn and unable to talk to people about issues or problems because she would cry. Relationships with her family were very strained: “I was going through really tough times.” When she enrolled in the trial, it was with the firm intention to “go back to the person I used to be.” This, of course, required a considerable change: she had to leave her home, to drive, to meet a new group of women whom she did not know and in unfamiliar surroundings. This woman reported that taking the decision to participate in the trial and “mixing with other people with my problem” was really good: “We got to talk, to express ourselves, what we had done.” The yoga classes provided an environment for everyone to share their ideas and experiences: “That aspect of sharing in what we had been through. That was really nice... Sharing the ideas is, I think, the best thing you can do.” She was happy to relate her story about the breast cancer and lymphoedema experience to the other women and valued listening to theirs. Calmer, more relaxed, more confident, she once again actively pursues her personal interests:

I look forward to doing things: go into the kitchen and start to cook a meal, do my beading, make my jewellery. Procrastination is a thing of the past: 'I know I have to do this and I'm not postponing anything, because that's what I used to do. I have to do that and go for it'. (#11)

She also has a much better relationship with others:

I want to get out, I am a lot more social now. My friend and I, we go for a walk, let's do this, or she'll give me a call or I'll ring her up: 'How're you going? What are you doing?' Keeping in touch with somebody makes all the difference because I can talk about things, not shutting myself away. (#11)

Moreover, little by little she is becoming physically stronger, more flexible and mobile:

I can move my arm better. In terms of movement, it worked for me, it really worked for me. I've got more movement... I am pushing myself to do it and it's doing me good, doing me a lot of good... I can move better. When I bend I can actually touch the floor now, which I haven't been able to do for a long time. (#11)

The yoga transformed her life, mentally, emotionally, physically. For this participant, it was a *Journey towards my former self*. (#11)

During interviews, participants were very conscious of the period when their breast cancer was being treated and the feeling of loss

of control. One recalled the fear and anxiety of not knowing much about her treatment or what was happening around her, having to put her trust in the professionals managing her care. She stated the following:

I did feel confident that everyone was definitely working for my best outcomes, but you just don't understand a lot about it... you just feel like you're in a boat that's being buffeted around, and doing all these things, and hoping everything's going to turn out alright. Unable to say: 'I don't want to do this' or 'I don't want to come to that appointment today. I'd rather do something else'. (#13)

Making the decision to participate in the trial restored a sense of control that she felt breast cancer had taken away and provided opportunities to interact and socialise with others around a shared experience.

I never really joined a support group or anything because I just thought I was one of those people that didn't really need to do that, but sometimes I wish I had because I've just realised through going to the classes how much better it makes me feel to know that other people go through the same things or similar things, and the different things they do. (#13)

The yoga trial was something that she chose to do herself, to help herself, without anyone saying: "This is what you should do." It was her decision; she was back in control of her life, a major development that has brought benefits to other areas of her life:

It's just made me think more outwardly and stop me focusing so much... because I think for a couple of years you just worry about every little medical thing and every little aspect of your body that's affected by all this. I feel like it's just taken that away from me. (#13: Back in control/Increasing my confidence)

5 | DISCUSSION

The interviews captured how this group of women responded to the yoga intervention and participation in the trial, contributing additional perspectives to the description of study outcomes represented by data obtained through the application of validated instruments (Loudon et al., 2014, 2016). Other trials studying the effect of yoga on women with BCRL have not reported narrative, subjective data (Douglass et al., 2012; Fisher et al., 2014; Narahari et al., 2016). Consequently, the approach adopted for this study adds a further dimension to understanding of the effects of yoga not previously published for women with BCRL.

The women in our trial spoke about benefit from participation in the study and the application of yoga to their lives. Improved well-being emerged as a major theme, important because women in other studies have reported the negative impact of lymphoedema across many aspects of their lives (Chun & O'Connor, 2011; Greenslade & House, 2006; Ridner, Bonner, Deng, & Sinclair, 2012; Towers, Carnevale, & Baker, 2008). Well-being is regarded as an important aid in dealing with chronic illness (Seligman, 2013). The gain in well-being described by these women was associated with improvements in their physical and mental health as well as their social lives. This is similar to results of another qualitative study detailing 13 women's responses to an 8-week yoga intervention for arm disability from breast cancer treatment, which included some women with BCRL (Thomas et al., 2014).

An essential component of yoga practice is the mindful awareness of the breath, body and thoughts. Practitioners are encouraged to develop a heightened awareness of the present moment. In our study, improved biopsychosocial functioning was often attributed to heightened awareness, both physical and mental, a finding also reported in other yoga studies for both ill and healthy populations (Evans, Sternlieb, Tsao, & Zeltzer, 2009; Thomas et al., 2014). For example, many spoke about their newfound awareness of their posture and their breathing, both of which can benefit those with secondary lymphoedema (Lymphoedema Framework, 2006).

Practices which focus on the present moment by directing awareness to physical sensations, feelings and reactions in a non-judgmental way are known generically as mindfulness (Smith, Richardson, Hoffman, & Pilkington, 2005). The reported health benefits of mindfulness have included stress reduction, improved mood and QOL (Carlson, Speca, Patel, & Goodey, 2003; Smith et al., 2005), fewer negative effects from treatment (Carson, Carson, Porter, Keefe, & Seewaldt, 2009; Chandwani et al., 2010), and increased self-regulation (Vago & Silbersweig, 2012). Mindfulness may contribute to reducing the negative effects of chronic illnesses, including chronic pain, by changing how the brain reacts to stimuli by creating altered and new neural pathways (Hölzel et al., 2011). As a holistic, mindful practice, yoga is also recommended for this purpose (Carson & Carson, 2016).

The emergence of a positive sense of self can be a powerful aid to recovery in ill populations (Breitbart, 2002) and is one aim of yoga interventions (Conboy, Wilson, & Braun, 2010). In the current study, calmness, well-being and reduced anxiety were attributed to the yoga, findings that have also been reported by participants in yoga trials after breast cancer treatment (Galantino et al., 2012; Thomas & Shaw, 2011) and stroke (Garrett, Immink, & Hillier, 2011) along with improved restful sleep. Improved sleep has been reported commonly after yoga interventions (Evans et al., 2009). A multicentre RCT consisting of 410 participants specifically aimed at those with sleep disturbances post cancer treatment reported improved sleep onset and quality with reduced need for medication after a 4-week yoga intervention (Mustian et al., 2013), some of whom may have had secondary lymphoedema. We have been unable to locate any

other study reporting on sleep improvement for women with BCRL using other interventions.

Women reported an emergence of an empowered self, which occurred also in another study for women with breast cancer (Galantino et al., 2012), in contrast to the reduced self-efficacy often described by those living with BCRL (Ridner et al., 2012; Thomas et al., 2014; Towers et al., 2008). A sense of optimism, hope and equanimity allowed participants to feel they had regained personal control of their lives while living with a chronic condition. Creating a means to change the locus of control from an external to an internal source can be a powerful aid to recovery (Breitbart, 2002; Oades, 2014). Referral to yoga classes may offer nursing and other health-care professionals a means to promote self-efficacy in their patients (Birdee, Sohl, & Wallston, 2016).

The deep commitment to the trial voiced by the women reflected a desire to help other women with BCRL (Girgis et al., 2011). Being part of a group, sharing experiences and providing support and encouragement to others can also contribute to well-being (Chun & O'Connor, 2011; McGrath, O'Malley, & Hendrix, 2011). For this group of women, the positive effect from the group interaction led to women sharing, often for the first time, their breast cancer experience and the continued fear that it may return. This fear has been reported in other studies (Girgis et al., 2011; Salonen, Kellokumpu-Lehtinen, Tarkka, Koivisto, & Kaunonen, 2011; Towers et al., 2008) and may indicate that participation in a group, such as that offered by attending regular yoga classes, provides another opportunity for personal growth and recovery after breast cancer and BCRL (Emslie et al., 2007; Ridner, 2005).

This was further demonstrated in the *Journeys* described by the nine women who felt the yoga experience had been instrumental in creating a profound personal and transformative change. Indeed, one of the central tenets of yoga is to enable "swastha" or the gradual acquisition of self-health, irrespective of one's diagnosis (Conboy et al., 2010) as shown in qualitative studies of yoga intervention after breast cancer treatment (Galantino et al., 2012; Thomas et al., 2014) and stroke (Garrett et al., 2011).

Participants reported improved levels of functioning and well-being that were only weakly associated with changes in the biomedical assessment of their lymphoedema and self-reported QOL using a validated instrument (Loudon et al., 2014, 2016). This suggests that clinicians should be aware of the limitations of standardised measures and monitor women's progress and the impact of treatment using a variety of techniques including anecdotal self-reports of functionality and well-being (Dawes, Meterissian, Goldberg, & Mayo, 2008; Pusic et al., 2013).

5.1 | Limitations

The group of rural women who volunteered for this trial were highly motivated, demonstrated by both their high level of compliance despite the fact that more than half of the women had to travel for an hour to an hour and a half to attend the yoga sessions. This, and the relatively small number of participants, means that the outcomes

may not be replicable in a larger population. Further, the yoga intervention was specifically tailored for those with BCRL by an experienced yoga and lymphoedema therapist. Other types of yoga may not produce similar results, especially when modifications may be required to suit the capability (or limitations) of participants. However, holistic therapies, such as yoga, do offer a range of practices that can be tailored according to the needs of the individual. Finally, this study relied on the women reporting improved functionality possibly as a result of reduced pain and heaviness, increased restful sleep and increased self-efficacy. These outcomes were not verified by objective testing nor is it known for how long such benefits could be maintained beyond the trial period.

6 | CONCLUSION

The interviews provided a textured account of participation in this trial of a yoga intervention for women with BCRL that has not previously been explored. Participants demonstrated a high level of commitment to the study and to each other. Such motivation may indicate not only the need for complementary self-management options but also the benefits of group activities for women with BCRL at some stage of their treatment. The participants of this study attributed a higher level of general well-being and awareness to their practice of yoga. Moreover, they clearly articulated the benefits to their physical, mental and social functioning they believed they had derived from participation in the trial.

The experience of being diagnosed with, and treated for, breast cancer was an ever-present reality for participants. Nonetheless, there was a general expression of empowerment and re-emergence. The breast cancer experience and BCRL were no longer something to hide from; the women were able to address the isolation, loss of self-esteem and lack of normalcy that can be associated with BCRL. Participants felt that yoga provided them with an opportunity to regain some personal control, which supports the potential of yoga to augment current self-management techniques for women with BCRL.

Further studies with other groups, greater number of participants, in different settings and with different styles of yoga, are warranted to fully assess the benefits of yoga as a useful adjunct to current self-management practices for women with BCRL. We also recommend that further trials in this area consider using mixed method approaches and collect both qualitative and quantitative data to gain a more comprehensive understanding of the impact and benefits yoga may have for women with BCRL. The qualitative data provided a voice for the women and captured information that was not apparent in the quantitative data collected.

7 | RELEVANCE TO CLINICAL PRACTICE

Yoga, with its current popularity and increasing availability, may offer a holistic practice that benefits women with BCRL in many domains of their lives and may be another self-management tool. Patients

who choose to augment their treatment of BCRL with yoga should be carefully assessed, taught an appropriate technique by a qualified yoga teacher/therapist and its impact monitored by their yoga teacher/therapist, breast care nurse, lymphoedema therapist or other practitioner responsible for their care.

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CONTRIBUTIONS

Study design: AL, TB, AW; Collected data: AL, MS, ED; Analysed data: AL, ED, TB; Prepared manuscript: AL, TB, AW.

CONFLICT OF INTEREST

No conflict of interest has been declared by the authors.

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