Understanding home monitoring and self-management in breast cancer-related lymphoedema: a qualitative study

Louise A Koelmeyer, Kerry A Sherman, John Boyages and Catherine M Dean

Key words

Bioimpedance spectroscopy, breast cancer, home monitoring, lymphoedema, qualitative study, self-management

Author details and declaration of interest: See p60.

s with many chronic conditions, such as diabetes and hypertension, the need to objectively monitor the signs and symptoms of lymphoedema, a side-effect of breast cancer treatment, is paramount for its long-term management (Kilgore et al, 2018; Koelmeyer et al, 2019). Lymphoedema may impact an individual physically, functionally, psychologically and financially (Hayes et al, 2008; Cormier et al, 2010; Hormes et al, 2010; Ancukiewicz et al, 2011; Armer et al, 2013; Perdomo et al, 2014; Boyages et al, 2016).

The key to managing this condition comprehensive education coupled with prospective surveillance for the early detection and management of subclinical lymphoedema (Soran et al, 2014; Whitworth and Cooper, 2018; Whitworth et al, 2018; Ridner et al, 2019). At-risk individuals are recommended to undergo routine measurements at cancer or therapy clinics on a 3-6 monthly cycle for at least 2 years (Stout Gergich et al, 2008; Dylke, 2019). Lymphoedema diagnosis typically occurs following clinically apparent fluid accumulation measured with standard techniques such as circumference-based measurements using a tape measure and

Abstract

The purpose of this qualitative focus group study was to gain an in-depth understanding of the attitudes of those at-risk of or living with lymphoedema following breast cancer towards the concept of lymphoedema home monitoring and whether it may be possible to do this using Bioimpedance Spectroscopy (BIS) technology. Thirty-one women with self-ascribed lymphoedema stage participated in one of five focus groups. Thematic analysis was used to identify five overarching themes regarding participant perspectives towards lymphoedema home monitoring to improve self-management: Lymphoedema knowledge; Facilitators of self-care; Barriers to self-care; Perceived control; and, Overall perceptions of home monitoring. The findings provided support for the concept of lymphoedema home monitoring and that BIS technology may potentially be used as an adjunct to support clinical consultations and self-management in lymphoedema.

self-assessment of visible swelling (Taylor et al, 2006). Yet, sub-clinical increases in extracellular fluid accumulation in at-risk limbs are not reliably detectable using these traditional measurement approaches (Koelmeyer et al, 2019).

Bioimpedance spectroscopy

Bioimpedance spectroscopy (BIS) addresses these measurement limitations by reliably identifying sub-clinical extracellular fluid accumulation using an "impedance ratio" methodology to assess unilateral lymphoedema of the arm (Ward, 2006; Ward et al, 2008). The device measures the electrical resistance of the limbs expressed as the unaffected:affected/at risk ratio (Ward, 2006). Alternatively, this ratio may be linearised and expressed as an L-Dex score which can be generated by the device (Ward, 2015).

Abnormal L-Dex values include those outside the normal range (-10 to +10 L-Dex units) and a change >10 from baseline, which is three standard deviations from the normative value (Czerniec et al, 2010). More recent research has suggested that a change of >6.5-7 L-Dex units from baseline (i.e. two standard deviations from normative) is more indicative of sub-

clinical lymphoedema (Fu et al, 2013). The current when taking a BIS measurement is imperceptible to patients and would be equivalent to that from an AA battery.

BIS technology has been used successfully in laboratory and clinical settings, including for patient self-measurement (Ridner et al, 2014a, 2014b; Koelmeyer et al, 2020).

A portable BIS device is available, with stainless steel contact electrodes built into the hand and foot plates. An individual can take measurements either sitting or standing. Data can be remotely monitored via the internet and stored in a secure cloud. This makes home-based objective monitoring possible for at-risk individuals (Koelmeyer et al, 2020).

It is unknown if women at risk of lymphoedema would be willing to adopt and engage with this type of home-based monitoring because it requires them to interact with new technology and undertake ongoing and regular measurements at home, and this may heighten anxiety for some. Ongoing self-monitoring will require women to make lifestyle changes, so it is important that willingness to engage with BIS monitoring is determined as a first step in implementing modifications to lymphoedema care.

Table 1. Characteristics of participants.	
Characteristic	n=31
Age (years), mean ± SD, (range)	60.77 ± 9.75 (42–75)
Marital status	n (%)
Married or partnered	19 (61.3)
Single	1 (3.2)
Divorced/separated	7 (22.6)
Widowed	1 (3.2)
Education	n (%)
Less than Year 10	2 (6.5)
Higher school certificate or equivalent	4 (12.9)
Vocational qualification	10 (32.3)
Undergraduate degree	7 (22.6)
Postgraduate degree	8 (25.8)
Time since diagnosed with breast cancer	n (%)
1–2 years	8 (25.8)
2–3 years	3 (9.7)
3–4 years	4 (12.9)
4–5 years	2 (6.5)
5–10 years	10 (32.3)
10–15 years	4 (12.9)
Type of lymph node surgery	n (%)
Sentinel lymph node biopsy	15 (48.3)
Axillary lymph node dissection	16 (51.6)
Time since diagnosed with lymphoedema	n (%)
No lymphoedema (at risk)	7 (22.6)
1–2 years	5 (16.1)
2–3 years	4 (12.9)
3–4 years	4 (12.9)
4–5 years	1 (3.2)
5–10 years	6 (19.4)
10–15 years	4 (12.9)
Lymphoedema stage	n (%)
No lymphoedema (at risk)	5 (16.1)
0	2 (6.5)
1	7 (22.6)
2	15 (48.4)
3	2 (6.5)

Aim

The objective of this study was to gain an indepth understanding of attitudes towards lymphoedema home monitoring using BIS and to explore potential factors associated with acceptance of this approach to self-management for those at-risk of or living with lymphoedema following breast cancer.

Methods

Participants and procedure

Women (*n*=31) were recruited through the Australian Lymphoedema Education, Research and Treatment (ALERT) Program's database at Macquarie University, Sydney, Australia. The eligibility criteria were: aged at least 18

years; previously diagnosed with breast cancer; and either at risk of, or living with, lymphoedema. Participants were required to attend a single 90-minute focus group session. Women who could not speak or understand English were excluded from the study. The Macquarie University Human Research Ethics Committee provided ethical approval for the study (Reference no. 5201500929).

Women self-reported their perceived lymphoedema stage according to International Society of Lymphology (2016) guidelines. Where possible, the five focus groups (n=5-8) were scheduled according to similarity in these self-reported stages of lymphoedema.

Women had not previously had access to or experience with any objective or formal technology to monitor their condition in the home. Demographic, medical and lymphoedema data were collected prior to the session using a paper-based survey. Focus groups were facilitated by an experienced occupational/lymphoedema therapist (LAK) and a research officer who took notes and supported the facilitator. Following written informed consent from participants the focus group sessions were audio taped, transcribed and checked for accuracy against the original recording. Each participant was offered the opportunity to speak and provide feedback to each question asked, ensuring that all women had the opportunity to share their own experiences and reduce the possibility of some women dominating the conversations.

To gain a general understanding of the lymphoedema status of all focus group participants, the facilitator initially welcomed participants and elicited discussion of the women's lymphoedema history and their perceived impact of lymphoedema on their daily life. Then, participants were asked a series of semi-structured questions to stimulate and guide discussion within the group addressing domains related to lymphoedema and its management:

- 1. Lymphoedema symptoms.
- Lymphoedema management strategies (i.e. clinic/therapist-based and home/ self-management).
- Monitoring lymphoedema, including objective (BIS technology) and subjective tools used by therapist and self.
- Use of and access to technology, such as computers and internet availability in the home.

Data analysis

Transcribed focus group data were independently coded by three researchers (LAK, KAS and VM) using thematic analysis (Braun and Clarke, 2006). Withincase codes were initially developed for each participant to capture information that was either salient for that participant or relevant to the research question. These codes were then categorised into sub-themes, and subsequently grouped into themes. The three coders discussed similarities and differences in coding, reaching 100% overall agreement.

Table 2. Participants in each focus group self-ascribed lymphoedema stage.						
Lymphoedema stage	Focus group 1 n (%)	Focus group 2 n (%)	Focus group 3 n (%)	Focus group 4 n (%)	Focus group 5 n (%)	
At risk	1 (20)	2 (29)	0 (0)	2 (33)	0 (0)	
0	0 (0)	1 (14)	0 (0)	1 (17)	0 (0)	
1	2 (40)	3 (43)	0 (0)	1 (17)	1 (20)	
2	2 (40)	1 (14)	7 (88)	2 (33)	3 (60)	
3	0 (0)	0 (0)	1 (12)	0 (0)	1 (20)	

Results

Participants

Thirty-one women, average age 60.77 years (± 9.75), participated in the study. Most were married. Over one-third of the women had been diagnosed with breast cancer within the previous 3 years, while nearly half had been diagnosed for more than 5 years. More than half of the women reported they were at high risk of developing lymphoedema because of an axillary lymph node dissection. Onequarter of the women reported they were at risk of or living with stage 0 or sub-clinical lymphoedema, while three-quarters of the women self-reported they had clinical lymphoedema across stages 1, 2 and 3. The participants' demographic characteristics are summarised in Table 1. Table 2 shows the number of women attending each focus group according to their self-ascribed stage of lymphoedema. Participants in focus groups number 1, 3 and 5 tended to have more participants with moderate clinical lymphoedema and groups 2 and 4 had those with more at-risk and earlier staged lymphoedema.

Following coding, five overarching themes were identified reflecting participants' views on lymphoedema and its monitoring, and attitudes towards technology:

- Lymphoedema knowledge
- Facilitators of self-care
- Barriers to self-care
- Perceived control
- Overall perceptions of home monitoring.

Several sub-themes were further identified within the overarching themes. *Table 3* identifies illustrative examples of quotes from participants in each of the themed domains. Pseudonyms were used to protect the identity of all participants.

Lymphoedema knowledge

Education to women at risk

Most participants felt it was important to be informed about lymphoedema, its

risk factors, risk reduction practices, early warning signs, symptoms to be aware of, strategies for monitoring and how to manage the condition.

Many shared mixed reports about the education provided to them from oncologists and surgeons. Some participants reported lymphoedema information being "not sufficient or considered a priority" and others feeling "totally informed" by their surgeon and oncologist. This seemed to relate to the timing of a participant's diagnosis – those more recently diagnosed appeared to be given more accurate information about lymphoedema.

Participants discussed how lymphoedema education needed to be "evidenced-based and current", as there are "many myths and misinformation in the community" and given soon after the breast cancer diagnosis; however, the "information needed to be given slowly over time and repeated" as sometimes it was too "emotionally overwhelming for them to absorb".

Understanding the concept of monitoring for lymphoedema

Participants who had been offered lymphoedema monitoring as part of their multidisciplinary care from the time of breast cancer diagnosis felt reassured that healthcare professionals were "keeping an eye" on things for them. Others who were not offered monitoring and subsequently developed lymphoedema indicated feeling regret for this lost opportunity of early detection and management.

Timing of using a device for monitoring

Participants unanimously agreed that ideally lymphoedema monitoring should commence at the time of breast cancer diagnosis. "Lymphoedema monitoring should be like another routine baseline test" that gives you information that can be used later to monitor change. A few participants reported that lymphoedema monitoring

was quick and easy using the L-Dex device so could almost "be taken each time you went to the clinic for any treatment".

Understanding of BIS reading

Participants commented that understanding in "layman's terms" of lymphoedema monitoring, including interpreting the L-Dex device and the normal L-Dex range, has helped them to be more aware of signs and symptoms of lymphoedema and what to do if they noticed any changes. Participants reported that getting immediate objective feedback was "lovely reassurance" that "everything's OK at the moment", and seeing whether the readings were stable was worthwhile and "gives you a sense of security."

Readiness for home monitoring

Participants reported that there is "a certain point in time which they would be ready or prepared to take on the responsibility" of home monitoring using a monitoring device to receive objective measurements, rather than just from their therapist. This point in time may be different for individuals, depending on their risk of developing lymphoedema, the intensity and physical effects of their medical treatment and everything else they are doing during this stressful time. Others said that "everyone's so different" and have "different coping and absorbing information" abilities. It was recommended that a variety of options are needed for all women to access and benefit.

Facilitators of self-care

Motivation for management

Several participants reported the importance of motivating themselves to self-manage their lymphoedema to keep it under control. Internal factors included positive thinking about the benefits of self-management and potential new treatments in the future, developing focused and realistic goals, and utilising coping mechanisms developed in previous life experiences. External

	Table 3. Illustrative quotations from participants describing the identified themes.				
Theme	Subtheme	Illustrative quotation	ISL lymphoedema stage	Participant (P) and focus group numbers	
Lymphoedema knowledge	Education to individuals at risk	"It should be given at the start, like it did for me, and then at all your appointments, because you're only taking in so much because it's a trauma you're going through."	At risk	P7 Group 2	
	Understanding concept of monitoring for lymphoedema	"You need to have a comparison. Are you getting worse are you getting better and that allows you to give yourself some indicators."	3	P5 Group 3	
	Understanding of L-Dex reading	"I guess you just need to know, obviously, the number of what you are, and if there's a range where you should be seeking more advice or doing more things, that would be helpful."	1	P2 Group 1	
	Readiness for home monitoring	"I think the therapist should be the person to make that suggestion to the person. Now I think you're at a stage where you should be able to monitor it and let that be a guide, someone to guide you through and then you can take over."	2	P7 Group 3	
	Timing of using home monitoring device	"That's where everyone's so different. And different coping and absorbing information."	2	P1 Group 4	
Facilitators of self-care	Motivation for management	"I was thinking that would be a real motivator to know [the L-Dex score], just to use it as a motivation tool to get out there and keep doing what you have to do. So for me it's the benchmark, and it's where the goal sits and it's the motivator to get it back down again."	0	P5 Group 4	
	Adherence to treatment	"I just do normal massage, wear my sleeve when I have to, so I've got it under control so hopefully I'll keep it at that."	2	P3 Group 3	
	Therapeutic relationship	"I met my therapist and she was very encouraging, and we just worked well together."	1	P6 Group 2	
	Feedback and reassurance	"I think for me, because I haven't any lymphoedema, just getting that L-Dex reading, it's just a lovely reassurance that everything's OK at the moment. So for me it's just that reassurance, and it's a preventative thing."	At risk	P3 Group 1	
Barriers to self-care	Coping	"That's where everyone's so different. And different coping and absorbing information."	2	P1 Group 4	
Perceived control	Empowerment	"I think it gives us more power as well. If we're in power of our own health, then we don't have to bother people like my therapist so much. And we can make our own decisions, and they're informed decisions and they're about our life. Knowing that this gardening will cause this; therefore, I know how much gardening I did, so, therefore, I know how much management I need to do on that today."	1	P5 Group 5	
	Confidence	"It [the L-Dex score] wouldn't stop me from doing anything. It doesn't stop me from doing anything now. But it would allow me to make an informed decision about things that I do. If my arm was a high L-Dex reading, well, I mightn't choose to do something that I worked out that increases it at that time."	2	P3 Group 5	

motivating factors reported included having a good partnership with a qualified therapist, a supportive partner and family, and having access to the latest evidence-based treatment.

Adherence to treatment/self-management Adherence to self-management tended to

be linked to knowledge and awareness of symptoms. If participants reported adhering to recommended evidence-based treatment and felt better, they tended to continue their own self-management. Comments such as "I wear my sleeve 24/7, I hate it in summer, but I know it's not worth going without it" were common amongst participants.

Therapeutic relationship

Partnering with a lymphoedema therapist was perceived as enhancing feelings of control, with comments such as "seeing my therapist helped me to feel more confident to do my own selfmanagement". Participants described their therapists as "the experts in knowing

Table 3. Cont	inuea.		l	
Perceptions of home monitoring	Perceived advantages of home monitoring	"Just getting that L-Dex reading, it's just a lovely reassurance that everything's OK at the moment."	2	P5 Group 1
	Perceptions of lymphoedema status	"What I mostly look for every day as soon as I get up, I'm checking, is this arm much fatter than this arm?"	1	P4 Group 1
	Immediate objective feedback	"I would use it [L-Dex device] quite a lot at the beginning until I got the feel for that and then I would know what to do. Because I know if I don't wear the sleeve for a couple of hours it's OK. But if I don't for half a day it is not OK. So then maybe I'll change my pattern of behaviour. Then I would like to use it [L-Dex device] again to check whether it's working."	1	P5 Group 5
	Confidence and reassurance	"I think it'd be great just to have a machine, so I know if it's [L-Dex score] suddenly going up or down, because I don't notice any different but having a machine would probably give me a bit more confidence to know, yes it is fine what I'm doing, or no you need to change it."	1	P2 Group 1
	Accessibility and usability of technology	"There are a lot of other women who don't have technology and who wouldn't have a clue how to use it. I've got friends my age, they've never worked, they've never really been exposed."	2	P6 Group 3
	Perceived limitations of home monitoring	"My idea is to deal with what you've got. Enjoy your life as much as you can. Do everything you possibly can. Just talking to some people, I think people would get worried and not do things. That would be my negative side of that whole thing. That's just me."	3	P2 Group 5
	Affordability	"I think one of the factors for me was having to give up work, my particular work and I didn't have any income coming in, even now, still trying to get back on my feet, it would be an issue, definitely."	At risk	P2 Group 4
	Technology	"I think you've got to get the people who are into technology to get into it first and then it filters down. I don't think you can go to the non-technology people and get them to start it up."	2	P7 Group 3
	Anxiety	"I don't think I'd want to try and do it [L-Dex measurement] each day. I would want to do it perhaps once a week and see how I go. But if I did it every day it then becomes a moment when you're anxious about things all the time. So I would prefer to perhaps weekly or maybe even longer, just to see."	1	P1 Group 2

the latest advances in treatment and it's important to have an overall management plan working in conjunction with the therapist".

Those who reported that their condition was well-controlled all agreed they had a positive relationship with their therapist who guided, supported and monitored them.

Feedback and reassurance

Several participants reported that seeing their therapist on a regular basis was able to provide them with feedback, reassurance and support regarding their self-management, and it was a "motivation tool to get out there and keep doing what you have to do".

Barriers to self-care

Stress and coping

Several participants described how having lymphoedema and the ongoing management of the condition impacts their quality of life and psychological wellbeing.

Those living with more advanced stages of lymphoedema often made comments such as "I think lymphoedema is often harder to cope with than the actual breast cancer because it's something that you've got for the rest of your life. This is one of the hardest things to grapple with and to manage."

Some participants reported lack of support from their partner or family members negatively impacted their coping and self-management. Others reported that general stress in the family impacted their ability to self-manage.

Perceived control

Empowerment

Most participants reported feeling empowered by having their lymphoedema or arm at risk being monitored regularly. Feedback about what the objective measurements mean in relation to their own self-management included comments such as "I'm a numbers person. And if I can get my numbers regularly, track it like that, then I'm comfortable and then I don't stress".

Confidence

Several participants reported feeling confident knowing what to do when the

objective measurements changed. They may have to change their self-management to "be more diligent with wearing their sleeve", or perhaps they "overused their arm in the garden" and needed to rest a little or spend less time gardening in one session.

Overall perceptions of home monitoring: Perceived advantages of home monitoring with a device

Participants shared how it would be useful to have a device that can take objective measurements to monitor their lymphoedema at home in between regular therapist reviews. Discussions surrounded the usefulness and practicality/feasibility of using a BIS home monitoring device. Participants discussed how useful it would be to have a device at home that you can use to "see whether there's a positive or a negative response to what you're doing so you can change what you're doing if required". Having a device may also give an individual "more confidence in their own self-management".

Perceptions of lymphoedema status

Many participants felt that having a home monitoring device would allow an individual to have an accurate objective perception of their lymphoedema status, indicating fluid levels and a gauge of the effectiveness of their own self-management. Getting such feedback "would influence how I manage it". Another participant agreed that having a device at home "would be a motivator to keep you on track without the inconvenience of always having to make an appointment to see your therapist".

Immediate objective feedback

Having objective feedback at home would allow an individual to change their selfmanagement based on the results and put their mind at ease or assist in reducing complacency. One participant shared how she "would not want to get too obsessive about only responding to the readings in isolation, rather than how the arm was feeling overall".

Confidence and reassurance

Several participants reported that having a home monitoring device would "probably give me more confidence to know, 'yes it is fine what I'm doing, or no you need to change'" and others reported that it gives you "more power" so that you do not have to visit your therapist if it is not really necessary.

Technology

Participants were all generally positive about using technology to operate a BIS home monitoring device. A few of the older participants said that they had access to internet and computers or smart devices; however, they would require some training in accessing and using the device to take a measurement and they may have to get "their family to assist".

Timing options for when to commence using a BIS home monitoring device were discussed, with many indicating it would be best for the therapist and individual to determine the right timing. Most thought it should not be commenced at the time of breast cancer diagnosis, as they would be too overwhelmed, and that education and clinic monitoring was needed before introducing home monitoring.

The timing of how often BIS measures should be taken at home also varied between participants. Generally, participants indicated that monitoring measurements should occur frequently initially to get an understanding of using the technology and any normal variation in readings, but that moving forward this frequency could be tailored to the individual. Some participants indicated that "daily to weekly [measurements] initially, then moving to monthly" would be appropriate, and that measurements should be taken more regularly for those who were deemed higher risk and in the first two years since breast cancer diagnosis to monitor for early detection of sub-clinical lymphoedema. Those with long-term clinical lymphoedema reported that they may only use the device "if they noticed symptoms or if they wanted to experiment with their self-management and gain feedback". A few participants reported that they would not want to take measurements too frequently as they would not want to be alarmed or worried by fluctuating readings or allow it to "dominate my life".

Participants were keen to receive their monitoring data in the form of an app that they could share with members of their multidisciplinary team. If they were monitoring themselves from home, participants indicated that guidelines were needed regarding what to do if the reading went outside the normal threshold limits, and how they would seek early intervention in a timely manner.

Perceived limitations of home monitoring with a device

Affordability

All participants reported that while they understood the value and practicality of the device, cost was an important factor when considering the feasibility of owning a device. "It would have to be affordable. I certainly understand that, because having lost all my income [during my treatment]... yes you want to be able to do it, but you have to be able to afford to do it with everything else."

Rental options were suggested. "I'd like to rent it first, see whether I use it... if we rented it and I used it, you then might consider buying it. Then that gives people an affordable option to try it before they commit." Another participant suggested having a "two-year rental plan like a mobile phone could be an option, so that you could monitor at home for the 2-year time when lymphoedema is commonly diagnosed".

Technology

Supporting people to build confidence in using the technology was regarded as important by participants, including accessing the internet and operating the device. Simple resources and training opportunities were noted as being critical to optimise usefulness of the monitoring programme.

Anxiety

Some participants discussed how they would need to have a good understanding of what the readings meant and how to access help if the readings started rising, to avoid increasing anxiety levels. The concept of home monitoring is to "reduce anxiety and I certainly don't want to be made paranoid about it [lymphoedema] developing".

Discussion

This qualitative study reported participants' experiences of being at risk of or living with lymphoedema following breast cancer treatment. It focused on identifying attitudes towards home monitoring using BIS technology and factors that assisted or limited participants' current self-management approaches. Tailored evidenced-based lymphoedema education at the time of breast cancer diagnosis and at regular intervals throughout the first 2 years was favoured by all participants, reflecting best practice guidelines (Stout Gergich et al, 2008; Kilgore et al, 2018; Whitworth et al, 2018; Dylke, 2019; Koelmeyer et al, 2019). Participants supported lymphoedema education and monitoring commencing in the clinic setting before introducing home monitoring to complement face-to-face consultations. Timing for introducing home monitoring may be dependent on the individual's lymphoedema risk factors, treatment side-effects and their levels of motivation.

participants reported Many importance of a positive and supportive relationship with their multidisciplinary breast cancer team, including a qualified lymphoedema therapist, to understand and adhere to their recommended selfmanagement. This support enables the women to feel confident and motivated to carry out self-management, consistent with research highlighting the importance of patient knowledge for optimal adherence to a self-management regimen (Sherman and Koelmeyer, 2011; Sherman et al, 2015; Alcorso et al, 2016a, 2016b).

Participants reported that receiving objective measurements via BIS home monitoring may positively affect adherence to self-management, but that it was important to have clear guidelines for how to action any elevations or fluctuations in readings.

It was agreed by participants that the frequency of home measurements should differ, with those at risk and/or in early stages of sub-clinical lymphoedema enacting more frequent measurements than those with more stable and advanced clinical lymphoedema. These views are consistent with evidence that BIS is one of the most effective measuring tools for determining sub-clinical changes before visible signs of swelling occur and guidelines for monitoring recommending three monthly intervals for the first two years after breast cancer diagnosis (Dylke, 2019, McLaughlin, 2020).

Providing education and self-monitoring of chronic health conditions has been shown to enhance the effectiveness of self-care, to enable the establishment of self-care goals and reinforce continuation of self-care (Ridner et al, 2014b). It is likely that being able to closely monitor and

obtain objective feedback on the impact of different lymphoedema self-care actions through devices such as home-based BIS will promote enhanced perceptions of behavioral control over lymphoedema (Hardeman et al, 2002; Ajzen, 2011; McEachan et al, 2011). This, in turn, should lead to improved motivation and enhanced adherence to self-care treatments (Ridner et al, 2014a, 2014b).

Study limitations

Notwithstanding these findings, certain limitations should be considered. Small of relatively numbers well-educated Australian women self-selected in these participate focus groups. Consequently, their views may not be representative of the general population of breast cancer survivors with lymphoedema generalisable to non-Australian women. Personal interviews and physical examinations were not conducted as part of this qualitative study. Therefore, there are no objective data to validate participants' self-reports of arm condition, symptoms or self-management regimens.

Conclusion

These findings provide support for the concept of BIS home monitoring as part of lymphoedema self-management and as an adjunct to clinical consultations. Future research is needed to ascertain the feasibility and acceptability of BIS home monitoring, as well as the specific benefits that can be derived from this approach both in terms of the women affected/atrisk, as well as lymphoedema therapists and healthcare professionals.

Acknowledgements: The authors thank Victoria Mule for assistance with data analysis.

Author details: Louise A Koelmeyer is Director of the Australian Lymphoedema Education, Research and Treatment Program, Department of Clinical Medicine, Faculty of Medicine, Health and Human Sciences, Macquarie University, Sydney, Australia; Kerry A Sherman is Professor and Health Psychologist, Centre for Emotional Health, Department of Psychology, Faculty of Medicine, Health and Human Sciences, Macquarie University, Sydney, Australia; John Boyages is Founding Director and Honorary Professor, Australian Lymphoedema Education, Research and Treatment Program, Department of Clinical Medicine, Faculty of Medicine, Health and Human Sciences, Macquarie University, Sydney and Radiation Oncologist, Icon Cancer Centre, NSW, Australia; Catherine M Dean

is Professor, Deputy Dean & Associate Dean Learning and Teaching, Department of Health Professions, Faculty of Medicine, Health and Human Sciences, Macquarie University, Sydney, Australia.

Financial support: This research was supported by a grant from ImpediMed Ltd (Brisbane, Australia) and the Australasian Lymphology Association (ALA) to the Australian Lymphoedema Education, Research and Treatment (ALERT) Program, Macquarie University.

Declaration of interest: LAK has acted as an education consultant to ImpediMed Ltd. JB is a stockholder in ImpediMed Ltd. ImpediMed Ltd had no involvement in the conception, design, execution, data analysis for this study or in the manuscript preparation. All other authors have no individual conflicts of interest or financial ties to disclose.

References

Ajzen I (2011) The theory of planned behaviour: reactions and reflections. *Psychol Health* 26(9): 1113–27

Alcorso J, Sherman KA, Koelmeyer L et al (2016a)
Psychosocial factors associated with adherence for selfmanagement behaviors in women with breast cancerrelated lymphedema. Support Care Cancer 24(1): 139–46

Alcorso J, Sherman KA, Koelmeyer L et al (2016b)
Perceived barriers to adherence to breast cancerrelated lymphoedema self-management. *Journal of Lymphoedema* 11(1): 20–6

Ancukiewicz M, Russell TA, O'Toole J et al (2011) Standardized method for quantification of developing lymphedema in patients treated for breast cancer. *Int J Radiat Oncol Biol Phys* 79(5): 1436–43

Armer J, Hulett J, Bernas M et al (2013) Best practice guidelines in assessment, risk reduction, management, and surveillance for post-breast cancer lymphedema. Curr Breast Cancer Rep 5(2): 134–44

Boyages J, Xu Y, Kalfa S et al (2016) Financial cost of lymphedema borne by women with breast cancer. Psychooncology 26(6): 849–55

Braun V, Clarke V (2006) Using thematic analysis in psychology. Qualitative Research in Psychology 3(2): 77–101

Czerniec SA, Ward LC, Refshauge KM at al (2010)
Assessment of breast cancer-related arm lymphedema –
comparison of physical measurement methods and selfreport. Cancer Invest 28(1): 54–62

Cormier JN, Askew RL, Mungovan KS et al (2010) Lymphedema beyond breast cancer: a systematic review and meta-analysis of cancer-related secondary lymphedema. *Cancer* 116(22): 5138–49

Dylke E (2019) Position Paper: Early detection of breast cancer-related lymphoedema. Australasian Lymphology Association. Available from: https://www.lymphoedema.org.au/public/7/files/Position%20 Statements/ALA%20Position%20Statement_Early%20 Detection%20of%20BCRL.pdf (accessed 05.07.2021)

Fu MR, Cleland CM, Guth AA et al (2013) L-Dex ratio in detecting breast cancer-related lymphedema: reliability, sensitivity, and specificity. *Lymphology* 46(2): 85–96

Hardeman W, Johnston M, Johnston D et al (2002)
Application of the theory of planned behaviour in behaviour change interventions: a systematic review.

Psychology & Health 17(2): 123–58

Hayes SC, Janda M, Cornish B et al (2008) Lymphedema after breast cancer: incidence, risk factors, and effect on upper body function. J Clin Oncol 26(21): 3536–42

Hormes JM, Bryan C, Lytle LA et al (2010) Impact of lymphedema and arm symptoms on quality of life in breast cancer survivors. *Lymphology* 43(1): 1–13

International Society of Lymphology (2016) The diagnosis and treatment of peripheral lymphedema: 2016

- Consensus Document of the International Society of Lymphology. *Lymphology* 49(4): 170–84
- Kilgore LJ, Korentager SS, Hangge AN et al (2018) Reducing breast cancer-related lymphedema (BCRL) through prospective surveillance monitoring using bioimpedance spectroscopy (BIS) and patient directed self-interventions. Ann Surg Oncol 25(10): 2948–52
- Koelmeyer LA, Borotkanics RJ, Alcorso J et al (2019) Early surveillance is associated with less incidence and severity of breast cancer-related lymphedema compared with a traditional referral model of care. Cancer 125(6): 854-862
- Koelmeyer LA, Ward LC, Dean C, Boyages J (2020) Body positional effects on bioimpedance spectroscopy measurements for lymphedema assessment of the arm. Lymphat Res Biol 18(5): 464–73
- McEachan RRC, Conner M, Taylor NJ, Lawton RJ (2011)
 Prospective prediction of health-related behaviours with
 the Theory of Planned Behaviour: a meta-analysis. Health
 Psychology Review 5(2): 97–144
- McLaughlin SA, Stout NL, Schaverien MV (2020) Avoiding the Swell: Advances in Lymphedema Prevention, Detection, and Management. American Society of Clinical Oncology Educational Book 40: e17–26. Available from: https://ascopubs.org/doi/full/10.1200/EDBK_280471 (accessed 05.07.2021)
- Perdomo M, Davies C, Levenhagen K, Ryans K (2014) Breast Cancer EDGE Task Force outcomes: assessment measures of secondary lymphedema in breast cancer

- survivors. Rehabil Oncol 32(1): 22-35
- Ridner SH, Bonner CM, Doersam JK et al (2014a)
 Bioelectrical impedance self-measurement protocol
 development and daily variation between healthy
 volunteers and breast cancer survivors with lymphedema.

 Lymphat Res Biol 12(1): 2–9
- Ridner SH, Shih YC, Doersam JK et al (2014b) A pilot randomized trial evaluating lymphedema self-measurement with bioelectrical impedance, self-care adherence, and health outcomes. *Lymphat Res Biol* 12(4): 258–66
- Ridner SH, Dietrich MS, Cowher MS et al (2019) A randomized trial evaluating bioimpedance spectroscopy versus tape measurement for the prevention of lymphedema following treatment for breast cancer: interim analysis. Ann Surg Oncol 26(10): 3250–9
- Sherman KA, Koelmeyer L (2011) The role of information sources and objective risk status on lymphedema riskminimization behaviors in women recently diagnosed with breast cancer. Oncol Nurs Forum 38(1): E27–36
- Sherman KA, Miller SM, Roussi P, Taylor A (2015) Factors predicting adherence to risk management behaviors of women at increased risk for developing lymphedema. Support Care Cancer 23(1): 61–9
- Soran A, Ozmen T, McGuire KP et al (2014) The importance of detection of subclinical lymphedema for the prevention of breast cancer-related clinical lymphedema after axillary lymph node dissection; a prospective observational study.

- Lymphat Res Biol 12(4): 289-94
- Stout Gergich NL, Pfalzer LA, McGarvey C et al (2008) Preoperative assessment enables the early diagnosis and successful treatment of lymphedema. *Cancer* 112(12): 2809–19
- Taylor R, Jayasinghe UW, Koelmeyer L et al (2006) Reliability and validity of arm volume measurements for assessment of lymphedema. Phys Ther 86(2): 205–14
- Ward LC (2006) Bioelectrical impedance analysis: proven utility in lymphedema risk assessment and therapeutic monitoring. *Lymphat Res Biol* 4(1): 51–6
- Ward L, Kilbreath SL, Cornish B (2008) Bioelectrical impedance analysis for the early detection of lymphoedema. In: Weissleder H, Schuchhardt C (eds.) Lymphedema Diagnosis and Therapy. Essen: Viavital Verlag
- Ward LC (2015) Bioelectrical impedance spectrometry for the assessment of lymphoedema: principles and practice.
 In: Greene AK, Slavin SA, Brorson H. Lymphedema.
 Springer International Publishing: Chamonix, 123–32
- Whitworth P, Cooper A (2018) Reducing chronic breast cancer-related lymphedema utilizing a program of prospective surveillance with bioimpedance spectroscopy. Breast J 24(1): 62–5
- Whitworth PW, Shah C, Vicini F, Cooper A (2018) Preventing breast cancer-related lymphedema in high-risk patients: the impact of a structured surveillance protocol using bioimpedance spectroscopy. Front Oncol 8: 197