Perceived barriers to adherence to breast cancer-related lymphoedema self-management

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Key words

Lymphoedema, patient adherence, self-management, breast cancer

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reast cancer-related lymphoedema (BCRL) is a chronic condition caused by lymphatic failure that occurs after damage to the lymphatic system as a consequence of surgery and radiation therapy (Ridner, 2013). More than 20% of women diagnosed with invasive breast cancer who have axillary clearance subsequently develop lymphoedema, often in their chest, breast or arm (DiSipio et al, 2013), although this falls to about 5% of those who have different treatment options, such as sentinel node removal (McLaughlin et al, 2008).

As breast cancer incidence and survival rates increase (Australian Institute of Health and Welfare, 2012), more women will be diagnosed with BCRL. Living with lymphoedema can be physically disabling due to symptoms including swelling, pain, discomfort, functional impairment and numbness (Fu and Rosedale, 2009). It also has a negative psychosocial impact, with women commonly reporting impaired quality of life (Tsuchiya et al, 2008; Mak et

Abstract

Background: Self-management is critical for the effective maintenance of breast-cancer related lymphoedema (BCRL), but levels of adherence are suboptimal. Aims: To compare the perceptions of lymphoedema therapists with those of women affected with BCRL regarding barriers to self-management. Methods: One-hundred-and-sixty-two women with breast cancer-related lymphoedema and 98 lymphoedema therapists were recruited. Participants completed an online survey assessing perceived barriers to adherence to lymphoedema self-management. Results: Multivariate analysis of variance indicated a significant difference between the extent to which therapists and affected women agreed that each of the seven perceived barriers negatively impact adherence. For each perceived barrier, therapists were more likely to agree that it negatively impacts adherence, while affected women were more likely to disagree that it negatively impacts adherence. Conclusion: The results suggest a need for improvements in communication between patients and care providers.

al, 2009), body image disturbance (Ridner et al, 2012; Fu et al, 2013; Rhoten et al, 2015; Teo et al, 2015), difficulties with employment (Fu, 2008), negative changes to relationships and sexuality (Radina et al, 2008), and psychological distress (Fu et al, 2013).

Women with BCRL can receive treatment from a lymphoedema therapist (a nurse, physiotherapist, occupational therapist or massage therapist) to reduce lymphatic fluid build-up in the affected Common treatments include therapist-assisted lymphatic drainage, bandaging, and pneumatic compression (Ridner, 2013). Lymphoedema therapists also prescribe a self-management regimen in order to maintain treatment outcomes and slow illness progression (Johnstone et al, 2006).

Lymphoedema self-management may involve a variety of behaviours including: wearing a compression garment; good skin hygiene to limit the risk of infection; avoiding injury to the affected area of the body; performing exercises; elevating the affected area; monitoring the affected area for changes in size, colour and temperature; and performing self-lymphatic drainage (massage) (National Lymphedema Network, 2011).

The development of lymphoedema can further damage the lymphatic system, starting a downward spiral of progression (Ridner, 2013), and so adherence to a self-management regimen is critical. Despite the importance of lymphoedema self-management, research suggests that adherence levels are suboptimal. Studies measuring adherence to self-management behaviours in women with BCRL have reported levels ranging from 13% to 79%, depending on the particular behaviour (Rose et al, 1991; Bani et al, 2007; Ridner et al, 2008; Tidhar and Katz-Leurer, 2010; Brown et al, 2014; Alcorso et al, 2015). For example, adherence to skin care is typically high (70%-98.2%)(Alcorso et al, 2015; Brown et al, 2014), whereas fewer women adhere to recommended exercises

(14%–70%). Lower adherence was found in a study evaluating the effectiveness of aqua lymphatic therapy (Tidhar and Katz-Leurer, 2010). Brown et al (2014) and Alcorso et al (2015) were both cross-sectional studes that found similar levels of adherence (approximately 70%).

In order to improve levels of adherence, it is important to understand factors influencing self-management behaviour. Several theories of health behaviour (Rosenstock, 1974; Bandura, include perceived barriers as a key factor that determines performance of the target behaviour, in this case lymphoedema selfmanagement. For example, the health belief model (HBM) (Rosenstock, 1974) proposes that barriers are one of the four factors influencing health behaviour, with a meta-analysis finding that barriers were one of the strongest predictors of health behaviour (Carpenter, 2010).

Barriers are also included in social cognitive theory (SCT) (Bandura, 1998), which distinguishes between personal barriers that influence beliefs about self-efficacy, such as a person's beliefs about whether or not he or she is able to perform the target health behaviour, and health resource barriers, such as access to medical care.

It is important to investigate perceived barriers to lymphoedema self-management, however, to date, little is known about potential barriers in this context. Beliefs about self-efficacy to overcome barriers to exercise in people with lymphoedema have been brought together in a lymphoedemaspecific exercise barriers self-efficacy scale. These barriers include concerns about appearance, the experience of symptoms of lymphoedema, fear of lymphoedema progression and lack of knowledge about the exercises (Buchan et al, 2015). However, perceived barriers to adherence to all of the recommended lymphoedema self-management strategies have not been specifically investigated quantitatively.

In qualitative studies, women have reported a number of barriers to self-management, including financial cost (to buy compression garments) (James, 2011; Ridner et al, 2011), physical limitations (James, 2011; Ridner et al, 2011), lack of time (Ridner et al, 2011; Radina et al, 2014), limited social support (James, 2011) and insufficient knowledge (Ridner et al, 2011). These are similar to the barriers reported by

people living with other chronic conditions, such as diabetes, arthritis and asthma, that also involve a self-management regimen (Jerant et al, 2005).

In addition to the barriers reported in qualitative research, there are two factors that may prevent women from following their self-management regimen. People with lymphoedema report that compression garments are uncomfortable and unattractive to wear (Lam et al, 2006; Pyszel et al, 2006; Ridner et al, 2012), and so concerns about their appearance may prevent women from wearing a compression garment.

Women living with BCRL have also reported difficulty accessing treatment (Barlow et al, 2014). If a woman has difficulty seeing a lymphoedema therapist for treatment she may not have adequate knowledge about how to manage the condition. Moreover, lack of access to a therapist may mean they do not have a prescribed self-management regimen that is regularly monitored by a trained therapist.

There has been no known study that has compared the perceptions of women with BCRL and of lymphoedema therapists regarding barriers to adherence to a selfmanagement regimen. More broadly, a comparison between health professionals' and patients' reported barriers to adherence has only been made for cancer screening. One study (Klabunde et al, 2005) found that both patients and physicians reported more barriers related to the patient rather than relating to the healthcare system to colorectal cancer screening, and both groups agreed that lack of awareness, lack of knowledge, and lack of recommendations were major barriers to adherence. However, the groups did not agree on all barriers. Physicians reported that patient embarrassment and the cost of screening was a barrier to adherence, but these were not major barriers reported by patients.

These findings indicate a degree of incongruence in the beliefs held by physicians and patients regarding perceived barriers to screening behaviours. In turn, it is possible that there will be differences between lymphoedema therapists and their patients regarding perceptions of barriers to lymphoedema self-management.

The aim of this study was to directly compare the perceptions of lymphoedema therapists with those of women affected with lymphoedema regarding barriers to adherence to self-management. The authors wanted to find out whether there would be significant differences between the extent to which affected women and therapists agreed that each barrier had a negative impact on self-management adherence.

Methods Participants

Women with BCRL

Australian women aged over 18 who were previously diagnosed with BCRL were eligible to participate in the study. After institutional ethics approval, women were recruited through a nationwide communitybased breast cancer organisation (Breast Cancer Network Australia BCNA), and three lymphoedema treatment clinics located in Sydney, Australia. Participants recruited from the BCNA (n=170) received an invitation sent via email from a BCNA staff member through the review and survey research pool of the BCNA. About 2000 women are registered members of the BCNA research pool although not all of these women had a diagnosis of lymphoedema. Participants from the lymphoedema treatment clinics were invited directly by clinic therapists who provided the women with an invite (n=30; response rate 28.8%). Invite letters and emails gave the web address to access the online patient information and consent form. In total, 200 women affected with lymphoedema responded to the online survey. After providing consent online, participants could complete the study questionnaire that was estimated to take 20 minutes.

Lymphoedema therapists.

Lymphoedema therapists were recruited through the Australasian Lymphology Association's National (ALA) Practitioners Lymphoedema Register (NLPR) which is a public register of lymphoedema therapists including nurses, physiotherapists, occupational therapists and massage therapists in Australia and New Zealand. Therapists that included an email address in their listing were sent an email invitation to participate in the study (n=146; response rate 82.2%). Email invitations gave the web address for the online patient information and consent form. After providing consent, participants continued on to the study questionnaire that was estimated to take 10 minutes to complete.

Table 1. Affected women with breast
cancer-related lymphoedema sample
characteristics $(n=162)$.

Variable	Mean (SD) or			
Age (years)	57.33 (10.13)			
Australian Aboriginal or Torres Strait Islander (%)	2			
Education (%)				
High school or less	22.2			
Some tertiary	38.3			
Tertiary degree or more	39.5			
Income (%)	1			
Less than \$50,000	35.8			
\$50,000-\$100,000	32.1			
\$100,000-\$150,000	21.6			
More than \$150,000	10.4			
Marital status (%)	'			
Married/partnered	80.2			
Divorced/separated	9.3			
Single	7.4			
Widowed	3.1			
Employment status (%)				
Full-time	29.6			
Part-time	24.1			
Retired	36.4			
Unemployed	9.9			
Type of LN Surgery (%)				
Sentinel node	12.8			
Axillary	78.8			
I don't know	8.3			
Received chemotherapy (%)	77.8			
Received radiation (%)	79.6			
Received HRT (%)	41.4			
Time since	5.12 (7.15)			
lymphoedema diagnosis (years)				
Lymphoedema severity ((%)			
Stage 0 (subclinical)	17.9			
Stage 1 (mild)	58.0			
Stage 2 (moderate)	22.2			
Stage 3 (severe)	1.2			
Unsure	0.6			
Note: LN = lymph node, I replacement therapy	HRT = hormone			

sample characteristics $(n=98)$. Variable Mean (SD) or	
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Occupation (%)					
Physiotherapist	49				
Massage Therapist	29				
Occupational Therapist	13				
Registered Nurse	9				
Years treating people with lymphoedema	9.42 (6.04)				
Practice location within Australia (%)					
New South Wales	29				
Queensland	20				
Victoria	17				
South Australia	9				
Western Australia	9				

3

0

10

Measures

Australian Capital

Northern Territory

Territory

Tasmania

Unknown

Perceived barriers to adherence

Each perceived barrier was measured using a 5-point Likert-type scale (0=strongly disagree, 5=strongly agree). Both affected women and therapists were asked to indicate how strongly they agreed or disagreed with each of seven barriers to self-management adherence as identified in the literature:

- Concerns about appearance (Lam et al, 2006; Pyszel et al, 2006; Ridner et al, 2012),
- Physical limitations (James, 2011; Ridner et al, 2011)
- Financial cost (James, 2011; Ridner et al, 2011),
- Time limitations (Ridner et al, 2011; Radina et al, 2014)
- Lack of social support (James, 2011)
- Access to treatment (Barlow et al, 2014)
- Lack of information (Ridner et al, 2011).

Sample characteristics

Demographic information collected from women with BCRL included age, Australian Aboriginal or Torres Strait Islander status, education level, income, marital status and employment status. Participants also provided information about their medical history, including time since lymphoedema diagnosis and details about their breast cancer treatment. Lymphoedema therapists were asked to provide information about their occupation and lymphoedema therapy practice, including the location of their practice (which specific state) and how long they had been treating people living with lymphoedema.

Data analysis

Descriptive statistics were calculated for participant characteristics and perceived barriers to adherence. All statistical analyses were conducted using SPSS version 21. A one-way multivariate analysis of variance (MANOVA) was conducted to determine if there was a significant difference between affected women and therapists' ratings for barriers to adherence to self-management. Posthoc comparisons were then undertaken to determine the specific barriers for which the patient and therapist samples differed in their views. Due to the number of analyses undertaken, the critical alpha was reduced to 0.01.

Results Sample characteristics

A total of 200 women with BCRL consented to participate in the study and the final sample was 162 after removing incomplete data (n=38). Sample characteristics for affected women are displayed in *Table 1*. A total of 120 therapists consented to participate in the study and the final sample of n=98 remained after removing incomplete data (n=22). Lymphoedema therapist sample characteristics are displayed in *Table 2*.

Perceived barriers to adherence

A multivariate analysis of variance (MANOVA) was used to compare affected women's and lymphoedema therapists' ratings on perceived barriers to self-management adherence. There was a significant overall main effect in perceived barrier ratings between therapists and affected women, F(7,251)=135.14, p<0.001. For each barrier, therapists were significantly more likely to agree that it had a negative impact on adherence, while affected women were more likely to disagree that it had a negative impact on adherence (*Table 3*).

Discussion

This is the first study to directly compare the beliefs of women with BCRL with those of lymphoedema therapists regarding perceived barriers to adherence to self-management regimens. As predicted, there was a significant difference between groups regarding the extent to which they agreed that each barrier negatively influenced adherence.

For each of seven statements about potential barriers to adherence (financial cost, negative appearance, physical limitations, time constraints, lack of social support, limited access to treatment and lack of information), therapists were significantly more likely to agree that these factors were salient barriers to adherence. In contrast, affected women were more likely to disagree that each potential barrier influenced adherence. This finding suggests there is a difference between beliefs held by affected women and those of therapists, and that therapists may not have an accurate understanding of the key factors underlying their clients' adherence to regimens.

That affected women disagreed that each potential barrier influenced their adherence conflicts with previous findings from qualitative research. Previously, women have reported that financial cost (James, 2011; Ridner et al, 2011), physical limitations (James, 2011; Ridner et al, 2011), a lack of time (Ridner et al, 2011; Radina et al, 2014), limited social support (James, 2011) and insufficient knowledge (Ridner et al, 2011) prevented them from following their self-management regimen. Inconsistent findings may be due to the relatively small sample sizes used in these qualitative studies (n=8-51) not being representative of the target population of women living with BCRL. In addition, only one of these studies was conducted in Australia (James, 2011) with the other studies being located in the US (Ridner et al, 2011; Radina et al, 2014). It is possible that the inconsistent findings reflect differences in culture and/or healthcare systems between these two countries. Finally, there may be other, more critical barriers to adherence faced by women with BCRL that were not captured in these studies.

An alternative explanation of these findings could be that adherence to self-management is not a high priority for these women, or that it is something that they do not regard as a concern. Although previous research has found suboptimal levels of adherence to self-management in women with BCRL (Brown et al,

2014; Alcorso et al, 2015), it is possible that the women in this study believe that they are doing well in self-managing their lymphoedema even if they are not 100% adherent. If women in this sample believe that they are currently successfully managing their lymphoedema, then it follows that they would not agree that any of the factors included in this study are indeed barriers for them. Furthermore, the majority of women in this study were diagnosed with subclinical (stage 0) or mild (stage 1) lymphoedema. It is possible that many of the patient participants may had have few symptoms of lymphoedema when they completed the survey and the questions about barriers to adherence may have been less salient.

There are potential limitations that must be considered when interpreting the results of this study. First, as this was the first study to quantitatively investigate perceived barriers to lymphoedema self-management, the measure of perceived barriers to adherence was created for the purpose of this study and has not been validated. There is the possibility that the statements used to represent each barrier do not accurately reflect the experience of women with BCRL, although they were informed by previous qualitative work in this area (Lam et al, 2006; Pyszel

Table 3. Comparison of responses to the statements about the perceived barriers to lymphoedema self-management adherence $(1 = \text{strongly disagree}, 5 = \text{strongly agree}).$								
	Affected women (n=162)	Therapists (n = 98)						
Barriers to adherence	M (SD)	M (SD)	F (1, 257)	p	Partial η2			
1. Concerns about appearance and clothing choice influence whether or not women wear their compression garments	2.13 (0.95)	4.07 (0.75)	297.89	<0.001	0.54			
2. Physical limitations or pain/discomfort prevent women from performing some or all of the self-care recommendations	1.91 (0.83)	3.83 (0.89)	304.87	<0.001	0.54			
3. The cost of compression garments prevents women from wearing them as often as recommended	1.82 (0.88)	3.63 (1.03)	225.06	<0.001	0.47			
4. Women do not have time to follow some or all of the self-care recommendations	1.94 (0.73)	3.33 (0.95)	172.50	<0.001	0.40			
5. A lack of social support (help from partner, family or friends with self-care, transportation, child care, etc.) prevents women from performing some or all of the self-care recommendations	1.70 (0.73)	3.69 (0.71)	457.72	<0.001	0.64			
6. Women have difficulty locating and/or traveling to a lymphoedema clinic or lymphedema therapist for treatment	1.94 (0.92)	3.94 (0.88)	307.19	<0.001	0.54			
7. Women require more information in order to properly manage their lymphoedema.	2.05 (0.80)	4.23 (0.78)	454.62	<0.001	0.64			

et al, 2006; James, 2011; Ridner et al, 2011; 2012; Barlow et al, 2014; Radina et al, 2014). Furthermore, there may be other, more influential, barriers to self-management adherence not included in this study. A second limitation of this study concerns the generalisability of findings. Only women with BCRL were included, and so the results may not extend to people with lymphoedema related to other types of cancer or primary lymphoedema.

Conclusion

In conclusion, differences were found between the affected women and the therapists' ratings of perceived barriers to adherence to self-management. Therapists were more likely to agree that each of seven potential barriers (concerns about appearance, physical limitations, financial cost, time limitations, lack of social support, access to treatment, lack of information) had a negative impact on adherence, while affected women were more likely to disagree that these factors had a negative impact on their adherence to self-management behaviours. Since adherence to self-management is critical for managing and slowing the progression of lymphoedema (Ridner, 2013), future research should investigate whether interventions targeting communication between patients and their care provider would be beneficial for increasing adherence to lymphoedema management regimens. Future research should also aim to identify what women with BCRL identify as the most influential barriers to adherence.

The findings of this study have implications for lymphoedema therapists and oncology nurses that work with women diagnosed with BCRL, such as oncologists, surgeons and nurses. The mismatch between affected women and lymphoedema therapists' beliefs about barriers to self-management adherence suggests a need for improvements in communication between the client and health professional. Healthcare professionals should aim to have an explicit discussion with women about barriers to self-management, as well as potential strategies to overcome these barriers. Furthermore, efforts to improve communication may have benefits for increasing adherence to lymphoedema self-management. This has been found before when patient-provider communication has been improved when relating to adherence to diabetes self-management (Heisler et al, 2002), which is similar to lymphoedema self-management in a number of ways and includes skin care, exercise and the use of compression garments (Cullum et al, 2001; Bains and Egede, 2011).

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