

# Factors associated with psychological distress in women with breast cancer-related lymphoedema

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## Abstract

**Background:** Previous research has shown that lymphoedema impacts negatively on an individual, including psychological distress and body image disturbance, particularly for younger women. This study identified psychological factors associated with distress in women with breast cancer-related lymphoedema and determined whether age moderated the specific relationship between body image disturbance and distress.

**Methods:** Australian women ( $n=166$ ) diagnosed with breast cancer-related lymphoedema were recruited through a community-based breast cancer organisation and lymphoedema treatment clinics. Participants completed an online survey assessing lymphoedema-related cognitions (personal control, perceived treatment effectiveness, and consequences of lymphoedema), perceived ability to self-regulate lymphoedema-related negative affect, body image disturbance, psychological distress (depression, anxiety and stress), and demographic/medical information.

**Results:** Beliefs about the consequences, perceived effectiveness of treatment and controllability of lymphoedema, perceived ability to self-regulate negative affect, body image disturbance, and number of lymphoedema symptoms were correlated with depression, anxiety, and stress scores. Multivariate regression analyses indicated that body image disturbance was significantly associated with depression, anxiety, and stress, and perceived treatment effectiveness was associated with stress. Age was a significant moderator of the relationship between body image disturbance and depression and anxiety, with older women with greater body image disturbance more distressed.

**Conclusions:** Health professionals need to be aware that women diagnosed with lymphoedema are at risk of experiencing psychological distress, particularly arising from body image disturbance and beliefs that treatment cannot control lymphoedema. Furthermore, older women may be at an increased risk of anxiety and depression arising from body image disturbance.

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Breast cancer-related lymphoedema is a chronic illness characterised by a build-up of fluid in the arm or chest wall arising from surgical or treatment-related damage to the lymphatic system [1–3]. More than 20% of women diagnosed with invasive breast cancer develop lymphoedema in one or both arms [4], with increasing prevalence because of rising breast cancer incidence and improved survival rates [5].

Living with lymphoedema can be physically disabling because of symptoms including swelling, pain, and functional impairment [2]. Lymphoedema also impacts negatively on the affected individual from a psychological perspective, with impaired quality of life [6], body image disturbance [7–9], and psychological distress [7] commonly reported. Symptoms of lymphoedema [6,10–12], and being poorly informed about lymphoedema and its management [13], have been linked with increased distress. Furthermore, inadequate social support and use of an avoidant coping style [10] have also been associated with lymphoedema-related distress.

Lymphoedema can cause significant bodily appearance changes because of extensive swelling which also affects

a woman's choice of clothing (e.g., being unable to wear slim fitting clothes) [7,9]. It is likely that lymphoedema-related body image disturbance will be associated with increased psychological distress, as body image disturbance generally has been associated with distress in breast cancer survivors [14], especially amongst younger women [15–17]. Qualitative research supports this view [8,18,19], as does one study that suggests that body image disturbance mediates the relationships between pain and body integrity beliefs, and pain and depression, in women with breast cancer-related lymphoedema [12]. Taken together, these findings suggest that younger women living with breast cancer-related lymphoedema will experience greater body image-related distress than older women.

Another factor that may be important for understanding psychological distress in women with breast cancer-related lymphoedema relates to specific illness representations held about lymphoedema. The common-sense model (CSM) [20] proposes that individuals form illness representations in response to health-related stimuli within a cultural, physiological, and psychological context. These

representations, including beliefs about the consequences and controllability (i.e., personal control over the illness and perceived effectiveness of treatment) of the illness guide a self-regulatory process that involves interpreting health-related stimuli, coping, and appraisal of outcomes [21]. No published studies have assessed illness representations in women with breast cancer-related lymphoedema; however, previous research has found that greater beliefs about the negative consequences of an illness and lower beliefs in the controllability of an illness are associated with increased levels of distress across multiple illness types [22], including breast cancer [23,24]. Hence, we would anticipate that these specific illness representations will be associated with distress experienced by an individual with breast cancer-related lymphoedema.

An inability to self-regulate negative affect may also underlie the development of psychological distress [25,26], because the way in which affect is consciously controlled can change the way an individual processes and responds to stimuli [27]. Women who are able to self-regulate negative affect that arises in response to different aspects of living with breast cancer-related lymphoedema may be less likely to experience distress. No studies to date have assessed the self-regulation of lymphoedema-related distress in women with breast cancer-related lymphoedema.

This study aimed to determine the factors that are associated with psychological distress in women living with breast cancer-related lymphoedema. Based on previous research, it was hypothesised that stronger beliefs in the negative consequences of lymphoedema, greater body image disturbance, and number of lymphoedema symptoms would be associated with greater distress, whereas stronger beliefs in the personal controllability of lymphoedema, perceived treatment effectiveness, and one's ability to self-regulate lymphoedema-related distress would be associated with lower distress. Consistent with findings from breast cancer [15–17], we further predicted that age would moderate the relationship between body image and distress such that younger women with greater body image disturbance will have higher levels of distress, in comparison to older women.

## Methods

### Sample and procedures

Australian women (18+ years), who were previously diagnosed with breast cancer-related lymphoedema, were eligible to participate in the study. Following institutional ethics approval, women were recruited through a nationwide community-based breast cancer organisation (Breast Cancer Network Australia (BCNA)), and three lymphoedema treatment clinics located in Sydney, Australia. Participants recruited from BCNA ( $n=170$ )

received an invitation sent via email through the BCNA research pool; participants from the treatment clinics were invited directly by clinic therapists who provided the women with an invitational letter ( $n=30$ ; response rate 28.8%). Invitational letters and e-mails provided the web address to access an online questionnaire that was estimated to take 20 min to complete.

## Measures

### Lymphoedema-related illness representations

Beliefs about the controllability, perceived effectiveness of treatment, and consequences of lymphoedema were measured using the Personal Control (e.g., 'Nothing I do will affect my lymphoedema'), Treatment Control (e.g., 'My treatment can control my lymphoedema'), and Consequences (e.g., 'My lymphoedema has major consequences on my life') subscales of the Revised Illness Perception Questionnaire (IPQ-R) [28]. The IPQ-R has been validated in a wide range of patient populations, including cancer patients [29]. Each item is rated on a 5-point Likert-type scale (1=strongly disagree, 5=strongly agree). Item reliability for the Personal control (6 items, possible range 5–30;  $\alpha=0.72$ ), Treatment control (five items, possible range 5–25;  $\alpha=0.79$ ) and Consequences (six items, possible range 5–30;  $\alpha=0.88$ ) subscales was satisfactory.

### Self-regulatory ability to manage lymphoedema-related distress

Self-regulation of negative affect associated with lymphoedema was measured using two items used in prior research [30] that are rated on a 5-point Likert-type scale (1=strongly disagree, 5=strongly agree): 'I believe that I am able to calm myself down when anxious or worried about lymphoedema'; and 'I believe I am able to limit the amount of stress experienced as a result of lymphoedema'. The item scores were summed to create a total score (2 items, possible range 2–10;  $\alpha=0.81$ ). Higher scores indicate better self-regulatory ability.

### Body image disturbance

A modified version of the Body Image Scale (BIS) [31] was used to measure body image disturbance. The BIS was originally developed for use with patients with breast cancer, and for this study items were reworded to be specific to lymphoedema (e.g., 'Have you felt less physically attractive as a result of your illness or treatment?' was reworded as 'Have you felt less physically attractive as a result of your lymphoedema?'). One item referring to dissatisfaction with the appearance of surgical scars from breast cancer was modified to refer to the appearance of the area of the body affected by lymphoedema. Ten items were assessed on a 4-point Likert-type scale (0=not at all, 3=very much). Item scores were summed (possible range

0–30;  $\alpha=0.94$ ), with higher total scores indicating greater body image disturbance.

**Psychological distress**

The short-form version of the Depression Anxiety Stress Scales (DASS-21) [32] is a standardised measure with Australian norms [33] for each subscale, and it was used to measure distress over the past 7 days. Each subscale consists of seven items (possible range for each subscale

0–21) on a 4-point Likert-type scale (0=did not apply to me at all – never, 3=applied to me very much – almost always). Item reliability for each subscale was satisfactory: depression ( $\alpha=0.92$ ), anxiety ( $\alpha=0.79$ ), and stress ( $\alpha=0.84$ ).

**Demographic and medical history variables**

Demographic information collected included age, Australian Aboriginal or Torres Strait Islander status, education,

**Table 1.** Demographic and medical characteristics of study participants ( $n = 166$ ) and associations with the DASS-21 subscales

Variable	Mean (SD) or %	Depression	Anxiety	Stress
Age (years)	58.04 (10.62)	$r < -0.01, p = 0.99$	$r = 0.03, p = 0.67$	$r = -0.03, p = 0.66$
Australian Aboriginal or Torres Strait Islander (%)	2.0	$r < -0.01, p = 0.89$	$r = -0.06, p = 0.46$	$r = 0.05, p = 0.56$
Education (%)		$r = -0.08, p = 0.32$	$r = -0.08, p = 0.33$	$r = 0.05, p = 0.52$
High school or less	22.9			
Some university	38.6			
University degree or more	38.5			
Income (%)		$r = -0.09, p = 0.28$	$r = -0.09, p = 0.25$	$r = -0.03, p = 0.73$
Less than \$50 000	29.1			
\$50 000–\$100 000	40.4			
\$100 000–\$150 000	19.2			
More than \$150 000	11.3			
Marital status (%)		$F(4, 162) = 1.08, p = 0.37$	$F(4, 162) = 0.15, p = 0.96$	$F(4, 162) = 0.95, p = 0.44$
Married/partnered	79.9			
Divorced/separated	8.3			
Single	7.1			
Widowed	4.1			
Employment status (%)		$F(4, 162) = 1.35, p = 0.23$	$F(4, 162) = 0.90, p = 0.51$	$F(4, 162) = 1.02, p = 0.42$
Full-time	30.8			
Part-time	23.7			
Retired	35.5			
Unemployed	10.0			
Time since lymphoedema diagnosis (years)	5.54 (5.49)	$r = -0.03, p = 0.69$	$r = 0.03, p = 0.73$	$r = 0.08, p = 0.30$
Type of LN Surgery (%)		$t(121) = -0.23, p = 0.82$	$t(121) = -0.27, p = 0.79$	$t(121) = -0.38, p = 0.71$
Sentinel node	10.7			
Axillary	62.7			
I don't know	26.6			
Received chemotherapy (%)	79.9	$r < 0.01, p = 0.96$	$r = 0.06, p = 0.46$	$r = -0.02, p = 0.81$
Received radiation (%)	76.9	$r = -0.03, p = 0.68$	$r = 0.12, p = 0.12$	$r = 0.07, p = 0.40$
Received HRT (%)	29.6	$r = -0.07, p = 0.35$	$r = -0.09, p = 0.24$	$r = -0.04, p = 0.58$
Number of symptoms	5.45 (2.41)	$r = 0.32^{**}, p < 0.01$	$r = 0.24^{**}, p < 0.01$	$r = 0.23^{**}, p < 0.01$

Note: HRT = Hormone Replacement Therapy, LN = lymph node.

\*\*Correlation is significant at the 0.01 level (two-tailed).

**Table 2.** Pearson's correlations between psychological distress and psychological variables

Variable	1	2	3	4	5	6	7	8
1. Depression	—	0.70**	0.67**	-0.32**	-0.30**	0.34**	-0.28**	0.55**
2. Anxiety		—	0.72**	-0.30**	-0.26**	0.30**	-0.23**	0.41**
3. Stress			—	-0.16*	-0.33**	0.31**	-0.19*	0.38**
4. Personal control				—	0.28**	0.19*	-0.32**	0.36**
5. Perceived treatment effectiveness					—	0.53**	-0.16*	0.43**
6. Consequences						—	-0.28**	0.50**
7. Self-regulation of affect							—	-0.25**
8. Body image disturbance								—
M	2.93	2.71	4.41	16.27	16.10	15.40	7.68	16.78
SD	4.18	3.32	3.88	2.33	3.34	3.27	1.40	7.08

\*\*Correlation is significant at the 0.01 level (two-tailed).

\*Correlation is significant at the 0.05 level (two-tailed).

**Table 3.** Hierarchical multiple linear regression analyses to determine factors predictive of psychological distress (depression, anxiety, and stress)

		Unstandardised coefficients		Standardised coefficients			
		B	SE	Beta	t	p	95.0% CI
<b>Depression</b>							
Step 1	Age	0.06	0.03	0.13	1.93	0.06	(-0.01, 0.11)
	Symptoms	0.24	0.12	0.14	1.96	0.05	(-0.01, 0.48)
	Personal control	-0.20	0.13	-0.11	-1.58	0.12	(-0.46, 0.05)
	Perceived treatment effectiveness	-0.08	0.10	-0.06	-0.77	0.44	(-0.27, 0.12)
	Consequences	0.03	0.11	0.02	0.25	0.80	(-0.12, 0.24)
	Self-regulation of affect	-0.27	0.21	-0.09	-1.30	0.20	(-0.67, 0.14)
	Body image disturbance	0.25	0.05	0.43	5.30	<0.01	(0.16, 0.35)
F		13.06				<0.01	
R <sup>2</sup>		0.36					
Step 2	Age x body image disturbance	0.01	0.01	0.78	2.16	0.03	(0.01, 0.02)
F for ΔR <sup>2</sup>		4.67				0.03	
ΔR <sup>2</sup>		0.02					
<b>Anxiety</b>							
Step 1	Age	0.05	0.03	0.13	1.84	0.07	(-0.01, 0.10)
	Symptoms	0.15	0.11	0.11	1.39	0.17	(-0.06, 0.36)
	Personal control	-0.21	0.11	-0.15	1.91	0.06	(-0.43, 0.01)
	Perceived treatment effectiveness	-0.07	0.09	-0.07	0.83	0.41	(-0.24, 0.10)
	Consequences	0.08	0.09	0.07	0.82	0.42	(-0.11, 0.22)
	Self-regulation of affect	-0.14	0.18	-0.06	-0.77	0.44	(-0.50, 0.22)
	Body image disturbance	0.12	0.04	0.26	2.95	0.01	(0.04, 0.21)
F		7.08				<.01	
R <sup>2</sup>		0.24					
Step 2	Age x body image disturbance	0.01	0.01	1.02	2.59	0.01	(0.01, 0.02)
F for ΔR <sup>2</sup>		6.70				0.01	
ΔR <sup>2</sup>		0.03					
<b>Stress</b>							
Step 1	Age	0.03	0.03	0.08	1.12	0.26	(-0.03, 0.09)
	Symptoms	0.13	0.13	0.08	1.06	0.29	(-0.12, 0.38)
	Personal control	-0.04	0.13	-0.03	-0.31	0.76	(-0.31, 0.22)
	Perceived treatment effectiveness	-0.21	0.10	-0.18	-2.11	0.04	(-0.42, -0.01)
	Consequences	0.07	0.11	0.06	0.64	0.52	(-0.15, 0.29)
	Self-regulation of affect	-0.21	0.21	-0.08	-1.00	0.32	(-0.64, 0.21)
	Body image disturbance	0.14	0.05	0.25	2.74	0.01	(0.04, 0.24)
F		5.75				<0.01	
R <sup>2</sup>		0.20					
Step 2	Age x body image disturbance	0.01	0.01	0.67	1.65	0.10	(-0.01, 0.01)
F for ΔR <sup>2</sup>		2.72				0.10	
ΔR <sup>2</sup>		0.01					

Note: CI = confidence interval.

income, and marital and employment status. Participants also provided medical information including time because lymphoedema diagnosis, lymphoedema symptoms, and breast cancer treatment (i.e., whether or not they received chemotherapy, radiation, and/or hormone replacement therapy; type of lymph node surgery).

### Data analysis

Descriptive statistics were calculated for the demographic, medical history, psychological, and outcome (distress) variables. Independent sample *t*-tests, one-way ANOVAs (categorical variables), and Pearson's (continuous

variables), Spearman rank (ordinal variables), and point-biserial (dichotomous variables) correlations were undertaken to determine the level of association between the outcome variables (depression, anxiety, and stress) and the demographic, medical history, and psychological variables, in order to identify covariates. Hierarchical multiple regression analyses were conducted with the illness representation variables, body image disturbance, and identified covariates to determine the significant predictors of distress, as well as the body image X age interaction. A priori calculation of minimum required sample size using G-Power [34] for multiple regression with five predictor variables (psychological variables) was  $n=134$  for a medium effect size of 0.10 and 80% power.

## Results

A total of 200 individuals initially consented to participate in the study and a final analysable sample of  $n=166$  remained after removing incomplete data ( $n=34$ ). Sample characteristics are displayed in Table 1. Of the demographic and medical variables, only number of lymphoedema symptoms was associated with depression, anxiety and stress scores (Table 1); hence, this variable was entered as a covariate in multiple regression models.

Mean scores for the distress subscales and psychological variables are displayed in Table 2. DASS-21 anxiety scores ( $M=2.71$ ,  $SD=3.32$ ) for this sample were significantly higher than for the Australian adult population norm ( $M=1.74$ ,  $SD=2.78$ ) [33],  $t(661)=3.70$ ,  $p<0.001$ , 95% CI [0.46, 1.49]. Scores on the depression  $t(661)=1.02$ ,  $p=0.31$ , and Stress  $t(661)=1.13$ ,  $p=0.26$ , subscales for this sample did not differ from Australian norms [33]. The mean BIS score ( $M=16.78$ ,  $SD=7.08$ ) was significantly higher than

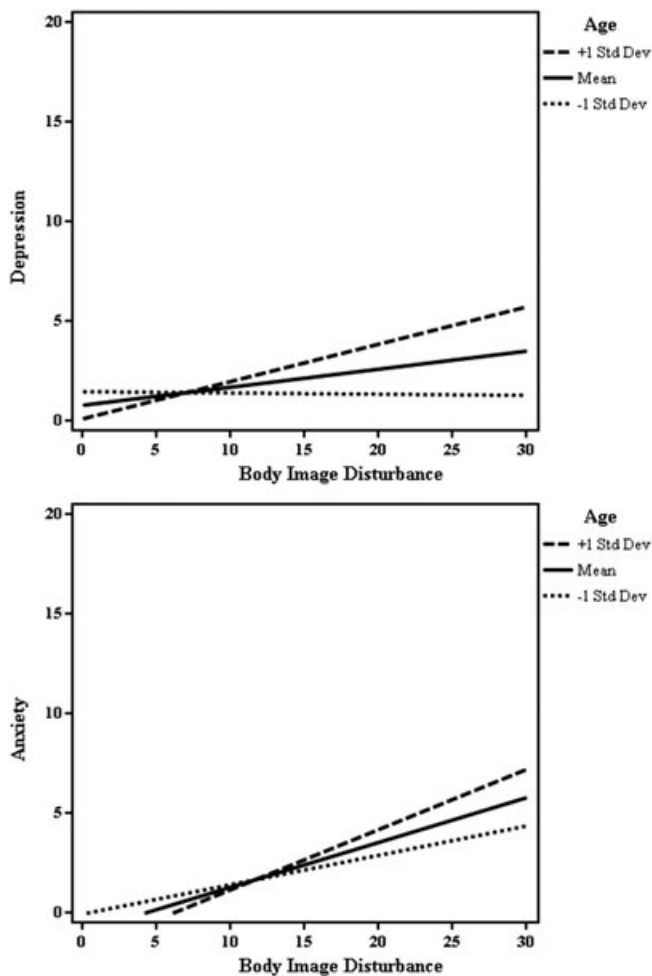
previously documented in the scale validation studies ( $M=8.07$ ,  $SD=5.02$ ) [31],  $t(442)=15.12$ ,  $p<0.001$ , 95% CI [-9.84, -7.58], and in a previous sample of women with breast cancer-related lymphoedema ( $M=12.27$ ,  $SD=8.03$ ) [12],  $t(218)=-4.51$ ,  $p<0.001$ , 95% CI [-6.78, -2.25].

Pearson's correlations between distress scores and psychological variables are also displayed in Table 2. Variables associated at  $p<0.10$  with each subscale of the DASS-21 were entered into a series of hierarchical multivariate linear regression models to determine predictors of depression, anxiety, and stress.

Results of the multiple linear regression analyses were similar for depression ( $F(8, 159)=12.28$ ,  $p<0.001$ ,  $R^2=0.38$ ), anxiety ( $F(8, 159)=7.25$ ,  $p<0.001$ ,  $R^2=0.27$ ), and stress [ $F(8, 159)=5.42$ ,  $p<0.001$ ,  $R^2=0.21$ ], indicating an overall significant model for each outcome variable (Table 3). For each distress subscale, body image disturbance was significantly associated with distress. In addition, perceived treatment effectiveness was significantly associated with stress scores. The body image disturbance X age interaction was significant for depression and anxiety only (Figure 1), whereby older women with greater body image disturbance were more distressed.

## Conclusions

This is the first quantitative study to investigate specific illness representations and body image disturbance associated with psychological distress (i.e., depression, anxiety, and stress) in women living with breast cancer-related lymphoedema. In this study, levels of anxiety were significantly higher than the Australian population norms [33], and body image disturbance was higher in these women, compared with previous studies of women with breast cancer [31] and breast cancer-related lymphoedema [12]. Unlike the present study, in the previous study of women with breast cancer-related lymphoedema [12] all participants had undergone surgical treatment for lymphoedema. It is possible that the treatment successfully reduced swelling for these women, which might explain why they did not report as high a level of body image disturbance as the women in the present study. That body image disturbance is a key issue for individuals affected by lymphoedema has been well documented [7–9], with many women reporting feeling unattractive, shame, and embarrassment because of the visible symptoms of lymphoedema (e.g., severe swelling) and/or wearing a compression garment [8,9,35]. These findings are consistent with previous accounts of how impactful lymphoedema is breast cancer survivors [7] and highlight the need for adequate psychological support of these women to cope with the challenges of this post-treatment complication.



**Figure 1.** The moderating effect of age on the relationship between body image disturbance (Body Image Scale score) and depression and anxiety.

It is not surprising that increased lymphoedema symptoms reported was associated with psychological distress, and this finding is consistent with previous research [6,10–12]. The extensive swelling, pain, and reduced physical functioning associated with lymphoedema has several impacts on women, including negatively affecting their self-identity and contributing to emotional disturbance (e.g., fear, sadness, and worry) [7].

As predicted, illness representations were associated with psychological distress. Women with low levels of beliefs that they could control lymphoedema, both personally and through treatment, and those who believed that lymphoedema has negative consequences, experienced higher levels of distress. Furthermore, perceived treatment effectiveness remained significantly associated with distress (stress) along with body image disturbance, when taking into account the number of symptoms reported and beliefs about personal control, perceived consequences, and self-regulatory ability in the regression analyses. This finding suggests that women who do not believe that treatment is effective for managing their lymphoedema are at an increased risk of experiencing stress. The association between illness representations and distress in this study is consistent with previous research in breast cancer [23,24] and other illnesses [22], and with the CSM, which proposes that an individual's illness representations influence coping responses and are part of the process of illness self-regulation [20,21].

Stronger belief in one's ability to self-regulate lymphoedema-related distress was negatively associated with psychological distress in these women, which is also consistent with the CSM [21]. Although this relationship was only present in the bivariate analyses and not the multivariate regression analyses, our results suggest that women who do not believe that they are able to effectively manage their lymphoedema-related distress are at a higher risk of experiencing distress. This is consistent with previous research from neuroimaging studies that found that the self-regulation of emotion is a key factor in the development of distress including major depressive disorder [27].

Also, as predicted, body image disturbance was positively associated with psychological distress, and with depression, anxiety, and stress in the regression analyses. Prior research with breast cancer survivors not affected by lymphoedema has found a similar association between distress and body image disturbance [14–17]. Furthermore, body image disturbance may mediate the relationship between pain and depression in women with breast cancer-related lymphoedema [12]. Taken together, these findings indicate that women with breast cancer-related lymphoedema are at particular risk of experienced distress arising from body image disturbance, highlighting the

need for appropriately targeted psychological support for these women.

Contrary to previous research in the breast cancer population that has reported younger women experiencing greater body image disturbance, and subsequently greater psychological distress [17], this study found that for women experiencing high levels of body image disturbance, older women experienced significantly greater levels of distress. Consistent with the broader evidence base in breast cancer, younger women reported significantly higher levels of body image disturbance in comparison to older women [15,16], yet body image disturbance was not associated with increased distress in the younger women, compared with older women. It is possible that a higher proportion of the younger women in this study are receiving psychological support compared with the older women, as younger adults are more likely to seek mental health support [36,37]. It is also possible that the younger women in this study are receiving greater levels of social support that may help them to better manage the changes to their bodily appearance, as younger breast cancer survivors have been found to have larger social networks [38]. Finally, the younger women in this study may have characteristics that serve as a buffer for experiencing distress related to the changes to their body caused by lymphoedema. For example, a previous study found that self-compassion mediated the relationship between body image disturbance and distress amongst breast cancer survivors [17], and this finding suggests a potential protective effect of self-compassion for distress. Future research should investigate these possible explanations to determine if they account for the unexpected moderating effect of age on distress and body image disturbance found in this study.

There are some limitations to keep in mind when interpreting the results of this study. These data were obtained from self-report only, and there was no objective measure of lymphoedema severity. However, a cross-sectional design and the use of an online survey allowed for a good sample size, and indicators of lymphoedema status were included, such as number of symptoms and time since diagnosis. Future studies could improve upon this approach by obtaining objectively verified lymphoedema diagnoses and staging from qualified therapists and clinics, to supplement self-report data on lymphoedema symptomatology.

These findings have implications for practice and research. Lymphoedema therapists and other health professionals involved in the care of women at risk of developing lymphoedema, or currently living with lymphoedema, need to be aware that these women are at risk of experiencing psychological distress and body image disturbance. Efforts should be made to screen patients for symptoms of depression, anxiety, and stress,

as well as body image disturbance, to determine which women may benefit from additional support. Future research should investigate potentially viable intervention strategies to help women cope with the impact of lymphoedema on their bodies as well as strategies to lower levels of distress. For example, interventions designed to improve women's beliefs in their ability to self-regulate lymphoedema-related distress may be beneficial.

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## Disclosures

No potential conflict of interest reported.

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