

**Adherence to self-management and psychological distress in women  
with breast cancer-related lymphoedema**

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## **Abstract**

Nonadherence to breast cancer-related lymphoedema self-management is suboptimal. In addition, women with breast cancer-related lymphoedema experience psychological distress associated with this chronic illness. Adopting a social-cognitive theoretical framework, the aim of this thesis is to identify cognitive and affective predictors of adherence to self-management behaviours and predictors of psychological distress in women living with breast cancer-related lymphoedema. To achieve this aim, a longitudinal study was conducted that measured adherence to self-management behaviours, psychological distress, and cognitive and affective factors at baseline, 6- and 12-months. An additional cross-sectional study was conducted to identify lymphoedema therapists' and affected women's beliefs about barriers to adherence to self-management. The findings from the empirical studies on adherence suggest that cognitive and affective factors are not informative for understanding self-management behaviour in women with breast cancer-related lymphoedema. Furthermore, a disconnect between therapists' and affected women's beliefs about barriers to self-management was identified, with therapists believing more strongly than the affected women that financial cost, time, concerns about appearance, difficulty accessing treatment, insufficient knowledge, and physical limitations negatively impact adherence. In contrast, a number of cognitive and affective factors significantly predicted distress. Based on the results from the longitudinal study, an online self-compassion based writing activity was developed to minimise distress and body image disturbance in this population of lymphoedema-affected women. The online intervention received moderate to high user acceptability ratings from women affected with breast cancer-related lymphoedema suggesting the potential viability of this

intervention. In sum, the findings from this thesis have important implications for researchers and health professionals. Regarding self-management, medical characteristics and knowledge were identified as important factors for identifying women at risk of nonadherence. In addition, it may be beneficial to screen women for symptoms of psychological distress and body image disturbance in order to identify who may benefit from additional psychosocial support.

## **Statement of Candidate**

This thesis is submitted to Macquarie University in fulfilment of the requirements for the degree of Doctor of Philosophy. This work presented in this thesis has not been submitted for a higher degree to any other university or institution.

This work is, to the best of my knowledge and belief, original and my own. Any sources of information used have been appropriately referenced and the extent to which the work of others has been utilised has been indicated in the Statements of Contribution by Authors.

Ethics approval for the research covered by this thesis was granted by the Macquarie University Human Research Ethics Committee on 26 July 2013 (REF: 5201300366) and 5 February 2015 (REF: 5201401083).

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Jessica Alcorso, alongside co-authors Kerry A. Sherman, Louise Koelmeyer, Helen Mackie and John Boyages, was intimately associated with generating the research concept resulting in this publication. In addition, Jessica Alcorso was primarily responsible for designing the study as well as collecting and analysing the data.

Jessica Alcorso was the primary contributor to preparing the publication manuscript by generating the first draft, editing the draft to incorporate the comments and feedback from the co-authors, and responding to journal comments and suggestions for revision.

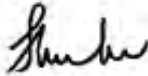
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## **Chapter 1. Introduction**

### **Background and rationale**

#### **The pathophysiology, incidence and treatment of lymphoedema.**

Lymphoedema is a chronic, progressive condition characterised by swelling that occurs when protein-rich fluid accumulates in the affected area of the body (Bernas, 2013; Ridner, 2013). There are two types of lymphoedema: Primary lymphoedema is caused by a developmental abnormality of the lymphatic system (Ridner, 2013) that affects approximately 1.15 in 100,000 individuals under the age of 20 (Smeltzer, Stickler, & Schirger, 1985), whereas the more frequently occurring secondary lymphoedema is caused by external damage to the lymphatic system (Ridner, 2013). Secondary lymphoedema is a common consequence of cancer treatment that involves surgical removal of lymph nodes (Bernas, 2013; Ridner, 2013) or damage to the lymphatic system resulting from radiation therapy (Bernas, 2013; Ridner, 2013; Shah & Vicini, 2011) and possibly chemotherapy (Cariati et al., 2015; Norman et al., 2010; Ridner, 2013).

Approximately one in five women treated for breast cancer will develop lymphoedema, with incidence rates higher for those who have undergone more extensive surgery (i.e., axillary-lymph node dissection in comparison to sentinel-node biopsy, greater number of lymph nodes removed) and who are overweight or obese (DiSipio, Rye, Newman, & Hayes, 2013). Women with lymphoedema in the upper body due to breast cancer may experience severe swelling, tingling, weakness, pain, limited physical mobility, numbness and stiffness (Hayes et al., 2011). If left untreated, or if poorly managed, lymphoedema may progress in severity through a series of stages: Stage 0 (or Ia; sub-clinical) is used to describe the condition when the lymphatic system

is not functioning optimally, but swelling is not yet present; Stage I (mild) is characterised by swelling that pits (indents) with pressure, but reduces when the affected area of the body is elevated; Stage II (moderate) is characterised by swelling and pitting, but elevation does not reduce limb volume; and, Stage III (severe) involves extensive swelling and the absence of pitting along with skin changes, fat deposition and fibrosis (International Society of Lymphology [ISL], 2013).

Although a cure for lymphoedema has not yet been developed, there are a number of treatment options and self-management strategies that can help slow or prevent the progression of the condition. The gold standard treatment consists of complete decongestive therapy (CDT), that entails two phases: 1) treatment (i.e., education, manual lymphatic drainage, compression bandaging, skin care and therapeutic exercise); and, 2) maintenance (i.e., self-management) (ISL, 2013; Merchant & Chen, 2015; National Lymphedema Network [NLN], 2011). The self-management of lymphoedema includes consistently following a regimen of practices that helps maintain treatment outcomes over the long-term, including wearing compression garments, self-lymphatic drainage, therapeutic exercises, skin and nail care, elevation, avoiding injury or trauma to the affected area and monitoring the affected area for skin changes and signs of infection (Merchant & Chen, 2015; NLN, 2011). Despite recent findings (Brown, Kumar, et al., 2014) that self-care adherence does not predict outcomes in breast cancer-related lymphoedema (e.g., reductions in limb volume or decreased symptoms), self-management is still recommended as a critical component of lymphoedema treatment (International Society of Lymphology, 2013; National Lymphedema Network, 2011). Other treatment options include intermittent pneumatic compression, which simulates manual massage, and low level laser therapy (ISL, 2013; NLN, 2011). For severe lymphoedema, surgical options are

available to help significantly reduce limb volume and improve symptoms (i.e., lymph node transfer and liposuction) (ISL, 2013; Merchant & Chen, 2015; NLN, 2011).

**Adherence to lymphoedema self-management behaviours.** As noted, the self-management of lymphoedema is a critical component of the overall treatment approach in order to maintain reductions in limb volume and slow the progression of the condition (ISL, 2013; Merchant & Chen, 2015; NLN, 2011; Ochalek, Gradalski, & Szygula, 2015). However, despite the importance of self-management, previous research suggests that adherence levels are suboptimal in both individuals with primary (non-cancer related) lymphoedema (i.e., 56%; Ridner, McMahon, Dietrich, & Hoy, 2008) and those with secondary (cancer-related) lymphoedema (i.e., between 13% to 79%; Bani et al., 2007; Brown, Cheville, Tchou, Harris, & Schmitz, 2014; Rose, Taylor, & Twycross, 1991; Tidhar & Katz-Leurer, 2010). Specifically, in women with breast cancer-related lymphoedema, adherence to self-management behaviours ranges from less than 30% (Tidhar & Katz-Leurer, 2010) to 69% (Brown, Cheville, et al., 2014). Levels of adherence appear to vary depending on the specific self-management behaviour. For example, in women with breast cancer-related lymphoedema lower adherence is often found for therapeutic exercise (e.g., 0-14%; Brown et al., 2014; Tidhar & Katz-Leurer, 2010) in comparison to skin care, for which adherence is generally quite high (e.g., 70%; Brown et al., 2014).

There is a paucity of research that has focused on adherence to lymphoedema self-management, hence there is little evidence to suggest what factors might underlie nonadherence. The variation in levels of adherence suggests that individual characteristics, particularly cognitive and affective factors, may influence adherence to lymphoedema self-management (Sherman & Koelmeyer, 2013). For example, psychological distress has been identified as negatively affecting adherence in women

with breast cancer-related lymphoedema (Newman, Brennan, & Passik, 1996; Ridner, Dietrich, & Kidd, 2011). Furthermore, social isolation has been reported as a barrier to self-management by individuals living with primary or secondary lymphoedema (James, 2011). We can further add to the information gained by these qualitative studies by quantitatively measuring the relationship between cognitive and affective factors and adherence to lymphoedema self-management. If we can determine what factors predict adherence and nonadherence to lymphoedema self-management, we may be able to identify individuals at risk of nonadherence and develop tailored interventions to improve adherence in this population, particularly if these factors are modifiable.

**Lymphoedema and psychological distress.** In addition to the burden of the physiological symptoms of lymphoedema (i.e., pain, swelling, reductions in physical functioning), there are a number of documented negative psychosocial impacts of the condition. From a social perspective, lymphoedema can lead to social isolation (Bogan, Powell, & Dudgeon, 2007; Fu & Rosedale, 2009; Towers, Carnevale, & Baker, 2008) and diminished sexuality and sexual functioning (Radina, Fu, Horstman, & Kang, 2015; Winch et al., 2015), as well as feelings of marginalisation in the health system (Ridner, Bonner, Deng, & Sinclair, 2012). Moreover, lymphoedema is associated with employment difficulties (Fu, 2008) and a financial burden of treatment costs (Shih et al., 2009).

From a psychological perspective, previous research has identified that lymphoedema can lead to negative changes in self-identity, including body image disturbance (Fu et al., 2013; Jäger, Döller, & Roth, 2006; Rhoten, Radina, Adair, Sinclair, & Ridner, 2015; Teo, Novy, Chang, Cox, & Fingeret, 2015) and perceived disability (Fu & Rosedale, 2009; Fu, 2008; Fu et al., 2013). In addition, women who develop breast cancer-related lymphoedema often experience greater psychological

distress compared with breast cancer survivors unaffected with lymphoedema (Chachaj et al., 2010; Dominick, Natarajan, Pierce, Madanat, & Madlensky, 2014; Khan, Amatya, Pallant, & Rajapaksa, 2012; Pyszel, Malyszczak, Pyszel, Andrzejak, & Szuba, 2006). Furthermore, the challenges of living with lymphoedema can elicit negative affect (i.e., unpleasant emotions such as fear, worry, anger and sadness) (Fu & Rosedale, 2009; Fu, 2008; Greenslade & House, 2006). Considering these numerous negative psychosocial impacts of lymphoedema, it is not surprising that individuals affected by lymphoedema report reduced quality of life (Chachaj et al., 2010; Heiney et al., 2007; Mak et al., 2009).

However, there is limited research on the factors associated with psychological distress in women with breast cancer-related lymphoedema. In order to identify women at-risk of experiencing high levels of distress as well as develop effective interventions to reduce psychological distress in these women, it is important to understand what factors predict psychological distress and understand their relationship with distress.

### **Theoretical framework**

A social-cognitive theoretical framework was used to inform the conceptualisation and design of the research outlined in this thesis. Specifically, the Common Sense Model (CSM) of illness self-regulation (Leventhal, Meyer, & Nerenz, 1980) and the Cognitive-Social Health Information Processing (C-SHIP) Model (Miller & Diefenbach, 1998) were used to inform the study hypotheses and identify which factors may underlie nonadherence to lymphoedema self-management, as well as psychological distress, in women living with breast cancer-related lymphoedema. These models were chosen as the theoretical underpinning of this thesis based on previous research in the at-risk population that found that adherence to risk-management

strategies in women at-risk of developing breast cancer-related lymphoedema aligned with the social-cognitive perspective of the CSM and C-SHIP model (Sherman & Koelmeyer, 2011; Sherman, Miller, Roussi & Taylor, 2015). Two additional models were considered: the Information-Motivation-Strategy (IMS) model and the COM-B system (Michie, van Stralen & West, 2011). Both the IMS model and COM-B system are recently developed models of health behaviour that focus on the role of patient motivation, capability and knowledge as well as contextual factors (e.g., social support) in predicting health behaviour. However, these two models were not incorporated into the framework of this thesis because neither have been directly tested to determine their usefulness in predicting health behaviour, in comparison to the CSM and C-SHIP models which are supported by literature.

This section will focus on explaining the key components and propositions of the CSM and C-SHIP model, previous research that has evaluated each model's usefulness for explaining health behaviour, and how the models were used to inform the study hypotheses.

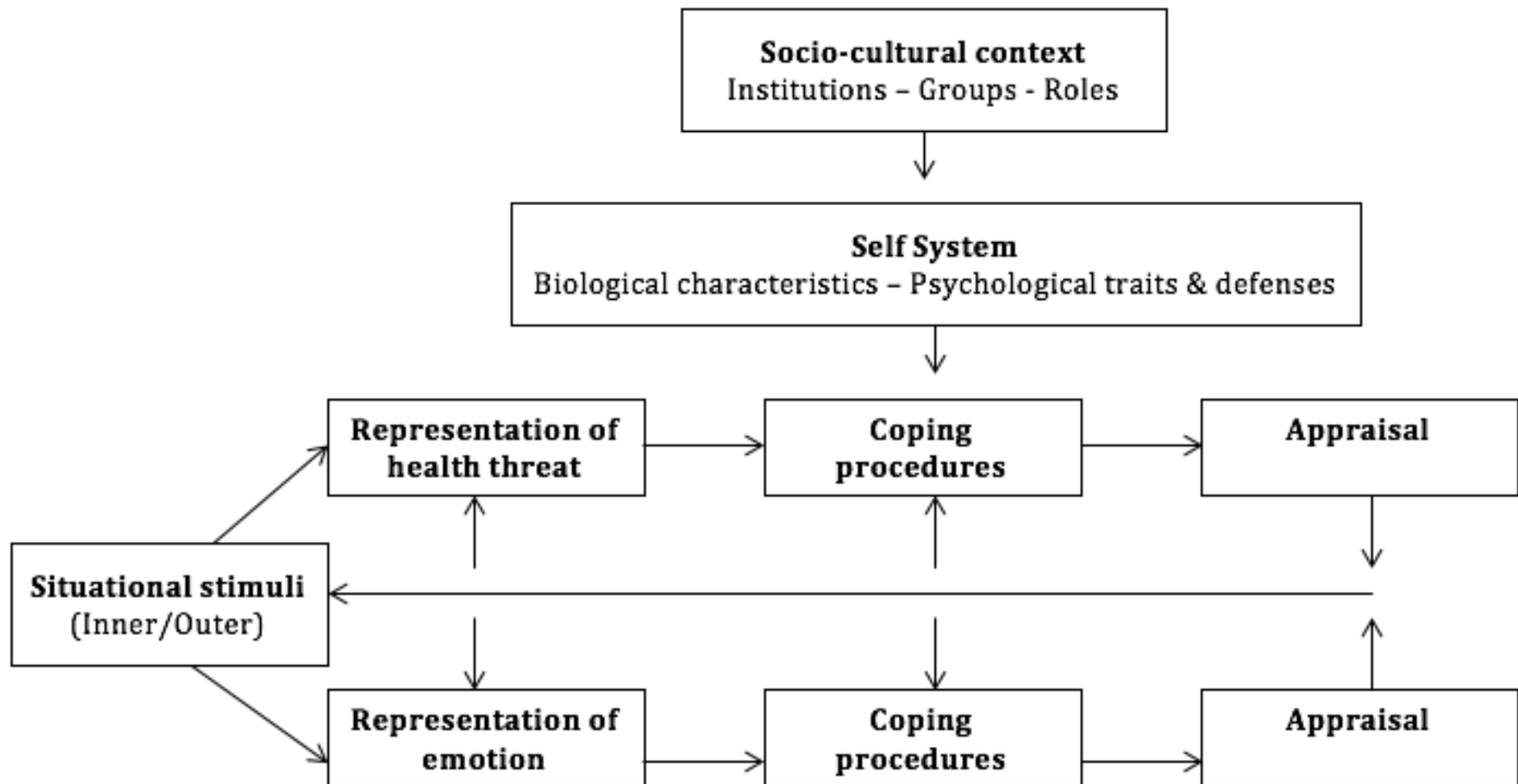
**The Common Sense Model (CSM) of illness self-regulation.** The CSM proposes that individuals form representations of illnesses that consist of cognitive beliefs about an illness (e.g., beliefs about the consequences or controllability of an illness) as well as emotional (affective) responses to illness (e.g., fear, anger or worry about an illness) (Diefenbach & Leventhal, 1996; Leventhal et al., 1980). These cognitive and affective illness representations are processed in parallel and influence coping responses (e.g., seeking help) and health-related behaviours (e.g., performing an illness-management behaviour such as wearing a compression garment or taking medication) (See Figure 1.1; Diefenbach & Leventhal, 1996; Leventhal, Diefenbach, & Leventhal, 1992). These illness representations are based on both external (e.g., health

professionals, media, family and friends) and internal (e.g., existing knowledge, experiencing symptoms and/or receiving a diagnosis) cues (Leventhal, Leventhal, & Contrada, 1998). In addition to cognitive and affective illness representations, another key component of this model is self-regulation, whereby the individual evaluates the cognitive and affective representations of her illness, chooses appropriate coping responses and behaviours, and appraises the outcomes of her behaviour (Diefenbach & Leventhal, 1996).

**The CSM and adherence to lymphoedema self-management.** The CSM predicts that illness representations, both cognitive and affective, are associated with health behaviours, and this is supported by studies investigating the relationships between specific illness representations and adherence to chronic illness self-management. A systematic review of 15 studies assessing CSM illness representations in both children and adolescents (Law, Tolgyesi, & Howard, 2014) as well as a meta-analysis of 30 studies assessing the CSM in adults (Brandes & Mullan, 2014) found that greater beliefs about the controllability of an illness are strongly related to higher levels of adherence to chronic illness self-management (e.g., diabetes, asthma and renal disease). There is also some (albeit mixed) evidence suggesting that lower illness-related negative affect (Law et al., 2014), greater beliefs about the negative consequences of an illness (Law et al., 2014) and greater illness coherence (i.e., the extent to which an individual believes he or she understands their illness) (Brandes & Mullan, 2014) are related to self-management adherence for illnesses including diabetes, hypertension and asthma. However, other illness representations, such as beliefs about the causes, identity (i.e., symptoms) and timeline (i.e., chronic/acute) of an illness seem to be only weakly associated with self-management adherence or not at all (Brandes & Mullan, 2014; Law et al., 2014).







**Figure 1.1** The Common Sense Model of illness self-regulation (adapted from Leventhal et al., 1992).



Illness representations in the lymphoedema context have only been measured in women regarded as being at-risk of developing breast cancer-related lymphoedema. Breast cancer survivors at risk of developing secondary lymphoedema due to cancer treatment are given a set of preventive guidelines to follow to minimise the risk of developing lymphoedema (risk-management strategies) (Bani et al., 2007). These preventive guidelines are similar to the lymphoedema self-management behaviours for affected women (e.g., avoiding injury or trauma to the arm or affected area; Bani et al., 2007). Consistent with the findings across chronic illness self-management in general, cognitive illness representations, including greater beliefs about the controllability and negative consequences of lymphoedema (Sherman & Koelmeyer, 2013), have been associated with adherence to lymphoedema risk-management behaviours in breast cancer survivors. Affective illness representations also seem to be important for understanding risk-management behaviours in this population: lower illness-related negative affect (Sherman, Miller, Roussi, & Taylor, 2015) as well as greater beliefs about one's ability to self-regulate negative affect (Sherman & Koelmeyer, 2013; Sherman et al., 2015) have been associated with adherence. Furthermore, in the at-risk population, one study found that cognitive illness representations are relatively stable over a 12-month period, whereas affective illness representations seem to change over time (Sherman et al., 2015). Specifically, lymphoedema-related negative affect decreased, while beliefs in the ability to self-regulate negative affect increased.

In sum, the findings from research on chronic illness self-management and lymphoedema risk management suggest that both cognitive and affective illness representations may be key factors underlying adherence in women with breast cancer-related lymphoedema. Thus, the CSM was used as a theoretical framework for this research to help inform the study hypotheses. Specifically, based on the CSM and

previous research it was predicted that greater beliefs about the controllability of lymphoedema, the negative consequences of lymphoedema and the ability to self-regulate lymphoedema-related negative affect would be associated with adherence to self-management. Furthermore, it was predicted that greater illness coherence and lower illness-related negative affect would also be associated with adherence to self-management.

**The CSM and distress.** The CSM predicts that cognitive and affective illness representations are associated with physical and emotional patient outcomes (Leventhal et al., 1998). For example, if a patient's beliefs about lymphoedema are violated, he or she may experience psychological distress (Leventhal et al., 1998). This is supported by research among women living with breast cancer-related lymphoedema that unexpected outcomes, such as more severe symptoms and a greater negative impact on activities of daily living than anticipated, can be a source of distress (Fu & Rosedale, 2009). Although no published studies have yet assessed illness representations in women with breast cancer-related lymphoedema; 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 psychological distress across multiple illness types (Hagger & Orbell, 2003), including breast cancer (Fischer et al., 2013; McCorry et al., 2013). Hence, it would be predicted that these specific illness representations should be associated with psychological distress experienced by women with breast cancer-related lymphoedema.

**The Cognitive-Social Health Information Processing Model (C-SHIP).** The C-SHIP model is similar to the CSM in that it incorporates cognitive and affective illness representations within a self-regulatory framework to explain health behaviours (Miller & Diefenbach, 1998). Cognitive illness representations are included in this

model as encodings (e.g., perceptions of risk or vulnerability of developing an illness) and beliefs (e.g., beliefs about self-efficacy to perform a certain health-related behaviour; Miller & Diefenbach, 1998). Affective illness representations (e.g., illness-specific fear or anger) are also included along with generalised distress (e.g., depression and anxiety) (Miller, Shoda, & Hurley, 1996).

Another similarity between the C-SHIP model and the CSM is the inclusion of self-regulatory processes, whereby an individual processes information and applies knowledge and strategies to choose appropriate coping responses and health-related behaviours (Miller, Shoda, et al., 1996). The C-SHIP model goes beyond the CSM by including goals and values as key factors influencing health behaviour. For example, the C-SHIP model would predict that an individual's health goals and how much he or she values being healthy would influence his or her likelihood of undertaking health protective or preventive behaviours (Miller, Shoda, et al., 1996).

**The C-SHIP model and adherence.** The C-SHIP model predicts that whether or not an individual engages in a health-protective behaviour, such as self-management or screening behaviour, can be explained by his or her illness encodings, expectancies, affect, goals and values and self-regulatory ability, as well as the interaction between these components. The model was initially applied to explain adherence to breast self-examination (Miller, Shoda, et al., 1996) and has since been applied to explain adherence across a variety of health behaviours, including cervical cancer control (Miller, Mischel, O'Leary, & Mills, 1996), smoking cessation counselling (Wen, Miller, Lazev, Fang, & Hernandez, 2012), and follow-up appointments for abnormal cervical cytology results (Hui et al., 2014). In the lymphoedema context, the C-SHIP model has been used as a framework for understanding adherence to lymphoedema risk-management strategies in breast cancer survivors (Sherman & Koelmeyer, 2013;

Sherman et al., 2015). As previously discussed in relation to illness representations and the CSM, greater beliefs about the controllability and negative consequences of lymphoedema (i.e., encodings and expectancies) (Sherman & Koelmeyer, 2013), lower illness-related distress (i.e., affect; Sherman, Miller, Roussi, & Taylor, 2015) and greater beliefs in the ability to self-regulate distress (i.e., self-regulation; Sherman & Koelmeyer, 2013; Sherman et al., 2015) have been associated with adherence in lymphoedema at-risk populations. Thus, the CSM and C-SHIP model can similarly explain adherence behaviour in the at-risk population in relation to cognitive and affective illness representations and self-regulation.

One factor included in the C-SHIP model as an illness-related expectancy that is not incorporated into the CSM is self-efficacy, an individual's belief in his or her ability to perform a certain health behaviour (Miller, Mischel, et al., 1996; Miller, Shoda, et al., 1996). Self-efficacy has not yet been measured in women affected by breast cancer-related lymphoedema, but in the research of women at-risk of developing breast cancer-related lymphoedema, beliefs about self-efficacy to perform risk-management strategies was associated with greater adherence (Sherman et al., 2015). In addition, self-efficacy has been associated with adherence in other chronic illnesses that involve self-management, such as diabetes (King et al., 2010) and asthma (Mancuso, Sayles, & Allegrante, 2010; Scherer & Bruce, 2001). Furthermore, self-efficacy is an important component of interventions that aim to improve the self-management of chronic illnesses and reduce disability (Marks, Allegrante, & Lorig, 2005). Therefore, based on the C-SHIP model and previous research, we would predict that beliefs about self-efficacy to perform lymphoedema self-management behaviours will predict adherence in women affected by breast cancer-related lymphoedema.

## **Aims**

In the preceding brief overview of the relevant CSM, C-SHIP and lymphoedema literature, two gaps in our knowledge about breast cancer-related lymphoedema were identified: (1) the factors predicting adherence to self-management behaviours, and (2) the factors predicting psychological distress in women living with breast cancer-related lymphoedema. Therefore, there are two aims of this thesis.

**Adherence.** The first aim was to identify psychological predictors of adherence to self-management behaviour in women with breast cancer-related lymphoedema in order to understand why women are, or are not, adherent. To achieve this aim, a longitudinal study was conducted that measured adherence behaviour and cognitive and affective factors (e.g., illness representations, self-efficacy, self-regulation of negative affect and knowledge about lymphoedema) at three time points (i.e., baseline, six months and 12 months). A longitudinal design was chosen to allow for the investigation of changes in adherence and cognitive and affective factors over time, as well as to allow for testing for predictors of adherence. The baseline data (collected at study enrolment) from this study were analysed to determine if specific factors found to be associated with adherence in the at-risk population (i.e., beliefs about the controllability and consequences of lymphoedema, self-efficacy, lymphoedema-related negative affect, self-regulation of negative affect and knowledge about lymphoedema; Sherman & Koelmeyer, 2011, 2013; Sherman et al., 2015) were also associated with adherence in the affected population. It was predicted that greater beliefs about the controllability of lymphoedema, the negative consequences of lymphoedema, self-efficacy to perform self-management behaviours and the ability to self-regulate lymphoedema-related negative affect would be associated with adherence to self-management. Furthermore, it was predicted that greater illness coherence and lower illness-related negative affect

would also be associated with adherence to self-management. To further add to our understanding of adherence behaviour in the breast cancer-related lymphoedema context, a cross-sectional study was conducted that compared beliefs about perceived barriers to adherence between women affected by breast cancer-related lymphoedema and lymphoedema therapists.

**Distress.** The second aim of this thesis was to identify psychological predictors of distress in women with breast cancer-related lymphoedema. In order to achieve this aim, the longitudinal study data were analysed for cognitive and affective factors associated with distress at baseline, as well as factors that predicted psychological distress at 12 months. It was predicted that greater beliefs about the negative consequences of an illness and lower beliefs in the controllability of an illness would be associated with increased levels of distress. Based on the preliminary findings of this study, a web-based self-compassion intervention was developed. To assess the feasibility and user acceptability of this intervention, a cross-sectional study was conducted with both consumers (i.e., women affected by breast cancer-related lymphoedema) and health professionals (i.e., nurses, physiotherapists, psychologists and other professionals with experience in lymphoedema and/or breast cancer).

### **Structure of this thesis**

This thesis comprises two parts. Part 1 consists of the work on adherence related to the first aim and contains two chapters: Chapter 2, a review of the literature considering psychological factors associated with adherence to lymphoedema self-management, and Chapter 3, research studies on adherence to lymphoedema self-management in women with breast cancer-related lymphoedema. Chapter 3 contains three manuscripts of which one is already published, one is currently under review and



one that has been prepared for initial submission. For published manuscripts, a copy of the paper has been inserted into the body of the thesis. For all accepted papers or those under review, the submitted version of the manuscript is included. Manuscripts that have not yet been submitted for publication are included according to APA 6<sup>th</sup> Edition formatting style. Each manuscript incorporates its own literature review/introduction, reports its own methods, results and discussion in detail and contains the relevant references.

Part 2 of the thesis consists of the work on distress related to the second aim. This part also contains two chapters: Chapter 4, a literature review on psychological distress in women with breast cancer-related lymphoedema, and Chapter 5, research studies on psychological distress in women with breast cancer-related lymphoedema. Chapter 5 contains three manuscripts, of which two have been published and one that has not yet been submitted for publication.

The thesis concludes with a general discussion (Chapter 6), which summarises the overall findings from both parts: adherence and distress. In this section the key findings from each research study are discussed in relation to each other, previous research and the overall theoretical framework of the thesis. The discussion also addresses the strengths and limitations of the thesis and directions for future research.

Following the discussion there are seven appendices that contain the participant information and consent forms and study questionnaires (Appendix A through C), ethical approval of studies and amendments (Appendix D), and oral and poster presentations (Appendix E through G).

## **Definitions of key terms**

*Adherence* – the extent to which an individual follows prescribed or recommended health behaviours and/or treatments given by his or her clinician (DiMatteo, Haskard-Zolnierrek, & Martin, 2012).

*Body image* – a multifaceted construct that includes an individual's cognitions, emotions and behaviours associated with his or her body and its functioning (Fingeret, Teo, & Epner, 2014; Teo et al., 2015).

*Body image disturbance* – concerns about one's body and/or difficulties adjusting to body image changes (Fingeret et al., 2014; Hopwood, Fletcher, Lee, & Al Ghazal, 2001).

*Body image investment* – the extent to which an individual values appearance and physical attributes as an important part of his or her self-worth (Chua, DeSantis, Teo, & Fingeret, 2015; Teo et al., 2015).

*Breast cancer-related lymphoedema* – Secondary lymphoedema due to breast cancer treatment. Approximately one in five women treated for breast cancer will develop lymphoedema, with incidence rates higher for women who have undergone more extensive surgery (i.e., axillary-lymph node dissection in comparison to sentinel-node biopsy and greater number of lymph nodes removed) and who are overweight or obese (DiSipio et al., 2013).

*Coherence* – the extent to which individuals understand or comprehend an illness (Moss-Morris et al., 2002).

*Consequences* – beliefs about the seriousness of the outcomes of an illness (Brandes & Mullan, 2014).

*Controllability* – beliefs about the extent to which an illness is responsive to personal behaviours (i.e., personal control) or medical treatments (i.e., treatment control) (Diefenbach & Leventhal, 1996).

*Illness representations* – individual's common-sense definitions of illnesses consisting of schematic representations across various dimensions, including the consequences of an illness, the controllability of an illness and illness coherence (Leventhal et al., 1998).

*Lymphoedema* - a chronic, progressive condition characterised by swelling that occurs when protein-rich fluid accumulates in the affected area of the body due to malfunctioning of the lymphatic system resulting from a developmental abnormality (primary lymphoedema) or external damage (e.g., cancer treatment; secondary lymphoedema) (Bernas, 2013; Ridner, 2013).

*Negative affect* – the experience of a negative feeling or emotion.

*Perceived barriers* – individuals' perceptions of the obstacles to performing a behaviour or achieving a particular outcome.

*Primary lymphoedema* – a chronic condition caused by a developmental abnormality of the lymphatic system (Ridner, 2013) that affects approximately 1.15 in 100,000 individuals under the age of 20 (Smeltzer et al., 1985);

*Psychological distress* – a concept most often operationally defined as a score on a self-reported patient outcome measure. These measures vary in terms of the specific construct(s) included, but they commonly assess depression, anxiety and/or stress.

*Psychosocial* – involving both psychological and social aspects, and the relationship of these perspectives with well-being.

*Secondary lymphoedema* – a chronic condition caused by external damage to the lymphatic system (Ridner, 2013). Secondary lymphoedema is a common consequence of cancer treatment that involves surgical removal of lymph nodes (Bernas, 2013; Ridner, 2013) or damage to the lymphatic system resulting from radiation therapy (Bernas, 2013; Ridner, 2013; Shah & Vicini, 2011) and possibly chemotherapy (Cariati et al., 2015; Norman et al., 2010; Ridner, 2013).

*Self-compassion* – the ability to fully accept oneself or show self-directed kindness while suffering (Raes, 2011) and involves three components: self-kindness, common humanity and mindfulness (Neff, 2003).

*Self-efficacy* - beliefs about one's ability to perform a certain behaviour or cope with a certain situation (Bandura, 1977)

*Self-management* – the behaviours undertaken by an individual to manage the symptoms, treatment, physical and/or psychosocial consequences that result from living with a chronic illness (Barlow, Wright, Sheasby, Turner, & Hainsworth, 2002).

*Self-regulation of negative affect* – the ability to effectively manage and cope with negative emotions and distress to maintain normal functioning (Sherman & Koelmeyer, 2013; Sherman et al., 2015).

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## **Part 1. Adherence**

The research in the first part of this thesis addresses the first aim: to identify cognitive and affective predictors of adherence to self-management behaviour in women with breast cancer-related lymphoedema in order to understand why women are, or are not, adherent. This part consists of two chapters. The first chapter (Chapter 2) is a literature review that examines previous research on adherence to self-management in the lymphoedema context. The second chapter (Chapter 3) is a collection of empirical studies conducted on adherence to self-management in breast cancer-related lymphoedema.



## **Chapter 2. Literature review: Factors associated with adherence to lymphoedema self-management**

Lymphoedema is a chronic and disabling condition arising from a malfunction of the lymphatic system that results in a build-up of protein-rich fluid in the body tissue, often in a limb, that leads to swelling, inflammation and fibrosis (Bernas, 2013; Hull, 2000). Primary lymphoedema develops as a result of a developmental abnormality of the lymphatic system, whereas the more frequently-occurring secondary lymphoedema is the result of external damage to, or removal of, parts of the lymphatic system (Ridner, 2013). Secondary lymphoedema is a frequent side effect from cancer treatment where damage to the lymphatic system arises from surgery and/or radiation therapy (Pinto & de Azambuja, 2011). It is difficult to estimate the prevalence of lymphoedema in the general population, but a systematic review found that primary lymphoedema develops in approximately 1.15 per 100,000 children and adolescents in North America (Rockson & Rivera, 2008). The risk of developing secondary lymphoedema as a result of cancer treatment is approximately 15.5% (Chang et al., 2010), and prevalence estimates vary depending on the type of cancer. For example, 21.4% of breast cancer survivors may develop lymphoedema post-treatment (DiSipio et al., 2013) in comparison to as many as 75% of head and neck cancer survivors (Ridner, 2013). Despite differences in aetiology, the clinical progression of both primary and secondary lymphoedema is virtually the same; moreover, similar treatment and self-management approaches are recommended for all individuals with a lymphoedema diagnosis (Mayrovitz, 2009; Ridner, 2013). For this reason, the two types of lymphoedema have been combined for the purposes of this review.

Living with lymphoedema can be physically disabling due to symptoms including swelling, pain, discomfort, functional impairment and numbness (Fu, Ridner, & Armer, 2009). Lymphoedema also impacts negatively on the affected individual from a psychological and social perspective, with impaired quality of life (Chachaj et al., 2010; Heiney et al., 2007; Mak et al., 2009), body image disturbances (Fu et al., 2013; Ridner et al., 2012) and increased psychological distress (Chachaj et al., 2010; Fu et al., 2013) commonly reported. Compounding the need to cope with the physical and psychological consequences of lymphoedema, the medical costs of treatment can be substantial, leading to financial stress in affected individuals (Shih et al., 2009).

The development of lymphoedema can further damage the lymphatic system, starting a downward spiral of progression (Ridner, 2013); hence, early intervention and ongoing self-management is a key priority. The effective management of primary and secondary lymphoedema involves a number of self-management approaches that rely on consistent enactment for minimising symptoms (e.g., swelling) and slowing illness progression (Johnstone, Hawkins, & Hood, 2006; Ridner, 2013). Self-management guidelines include behaviours such as wearing a compression garment, practicing good skin hygiene to limit risk of infection, avoiding injury or trauma to the affected limb (or body part), and performing self-lymphatic drainage (massage) (International Society of Lymphology, 2013; National Lymphedema Network, 2011). Patient education is needed to ensure that affected individuals understand how to follow the self-management guidelines to effectively maintain treatment outcomes and prevent further progression of their lymphoedema (Andersen, Højris, Erlandsen, & Andersen, 2000; Forner-Cordero, Muñoz-Langa, Forner-Cordero, & DeMiguel-Jimeno, 2010; Johnstone et al., 2006; Lasinski, 2013; Vignes, Porcher, Arrault, & Dupuy, 2007).

One study (Ridner et al., 2008) measuring adherence to a home-based treatment system in individuals diagnosed with lymphoedema reported only moderate overall levels of adherence at best, with adherence among individuals with primary (non-cancer related) lymphoedema (56%) greater than those with secondary (cancer-related) lymphoedema (32%). Other studies measuring adherence to self-management behaviours in individuals with secondary lymphoedema have reported levels varying from 13% to 79% depending on the particular behaviour (Bani et al., 2007; Brown, Cheville, et al., 2014; Rose et al., 1991; Tidhar & Katz-Leurer, 2010). For example, adherence to skin care is generally high (Brown, Cheville, et al., 2014), but adherence to exercise is often low (Rose et al., 1991; Tidhar & Katz-Leurer, 2010). Thus, despite the importance of patient adherence to lymphoedema self-management, research suggests that adherence levels are suboptimal. Recent evidence suggests that levels of adherence or nonadherence are relatively stable (Brown, Cheville, et al., 2014), but it is not clear what factors underlie the enactment of these recommendations.

The variation in levels of adherence suggests that individual characteristics, particularly cognitive and affective factors, may influence general adherence to self-management guidelines. For example, individuals living with lymphoedema have reported that social isolation negatively affects their ability to self-manage the illness (James, 2011). In addition, psychological distress in breast cancer survivors diagnosed with lymphoedema has been identified as a barrier to adherence (Ridner, Dietrich, & Kidd, 2011). Given the link between the physical symptoms of lymphoedema and psychological distress (Tsuchiya, Horn, & Ingham, 2008), there is a very real likelihood of a vicious cycle developing whereby lymphoedema symptoms lead to distress, which in turn leads to lower adherence, which then exacerbates symptoms. Breast cancer survivors at risk of developing secondary lymphoedema due to cancer treatment are

given a similar set of preventive guidelines to follow to minimise the risk of developing lymphoedema (Bani et al., 2007). Emerging evidence from research within this population also suggests that psychological factors such as knowledge (Bosomptra et al., 2002; Sherman & Koelmeyer, 2011; Sherman et al., 2015), cognitive and affective illness representations and self-regulation of affect (Sherman & Koelmeyer, 2013; Sherman et al., 2015) play a role in influencing adherence to the lymphoedema risk minimisation recommendations.

These findings are consistent with social cognitive and self-regulatory theories of health behaviour, such as the Common Sense Model (CSM) of illness representations (Diefenbach & Leventhal, 1996) and the Cognitive-Social Health Information Processing (C-SHIP) model (Miller & Diefenbach, 1998) that an individual's behaviours in light of a health threat will be a function of their cognitive and affective representations of that illness. Within the lymphoedema context, this theoretical perspective predicts that for a woman diagnosed with this condition, her adherence to self-management behaviours will be a function of the specific beliefs that she holds about lymphoedema (e.g., how effective the self-management behaviours are at controlling lymphoedema, her personal ability to carry out the recommended behaviours, and perceived consequences of lymphoedema) and her emotional representations (e.g., lymphoedema-related distress and worry and her ability to manage any distress).

In summary, previous research from both the affected and at-risk populations suggest that there are medical/clinical factors and patient-specific characteristics that will influence adherence to the self-management regimen. In order to understand why some individuals are adhering to their self-care recommendations when others are nonadherent, we need to consider a broad range of factors that may underlie the



enactment of these behaviours. In particular, if improving treatment outcomes and relieving symptoms for patients is a priority, it is important to identify which patients are at risk of being poorly adherent in order to intervene early to maximise patient wellbeing. However, to date, no published study has reviewed the evidence base to identify factors associated with adherence in the lymphoedema context. Given the infancy of this line of research, a scoping review was undertaken to describe the current knowledge base on factors associated with adherence to lymphoedema self-management and identify gaps and weaknesses that can be addressed by future studies.

## **Method**

### **Scoping review**

To date, there is no consensus on a specific methodology to be used for scoping reviews; however, the evidence-based PRISMA (preferred reporting items for systematic reviews and meta-analyses) guidelines (Moher, Liberati, Tetzlaff, & Altman, 2009) have been recommended by previous authors (e.g., Pham et al., 2014). Thus, a scoping review guided by the PRISMA statement was conducted to identify published research, both qualitative and quantitative, that examined factors associated with patient adherence to lymphoedema self-management recommendations.

### **Literature search strategy and inclusion criteria**

Eight databases were searched: PsycINFO, Cochrane Library, EMBASE, MANTIS, CINAHL, Sage, MEDLINE and AMED using the search terms: ('lymphedema' OR 'lymphoedema') AND ('adherence' OR 'compliance' OR 'treatment compliance' OR 'patient compliance' OR 'treatment adherence' OR 'patient adherence'). Searches were limited to "human" population and "English language". A

total of 199 articles were identified. The abstracts of these articles were screened and 86 were excluded due to not relating to breast cancer-related lymphoedema and/or not measuring adherence. Of the 64 full-text articles screened, five remained after removing duplicates and applying the exclusion criteria (see Figure 1.1).

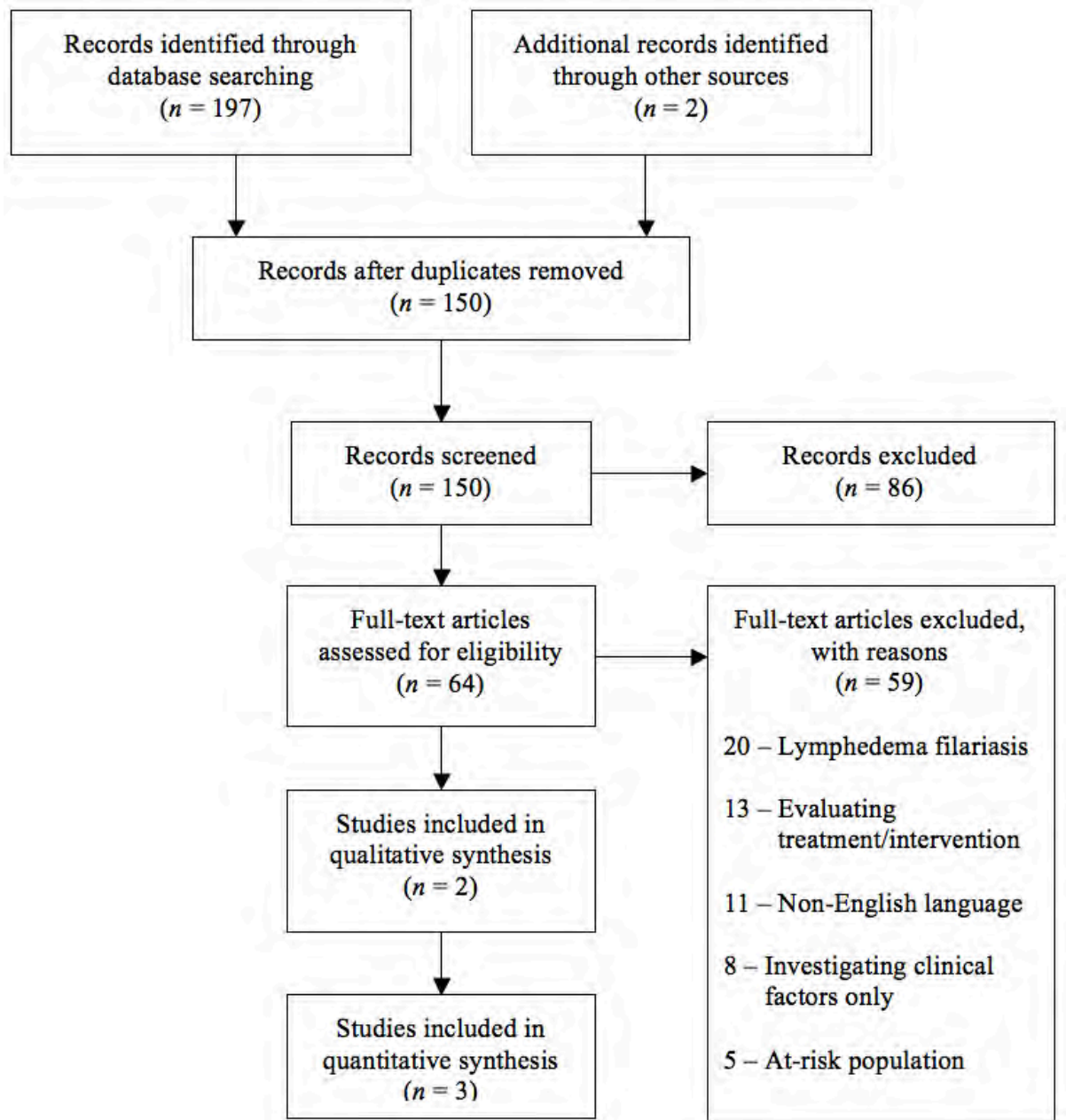
### **Data extraction and analysis**

The following information was extracted from the included articles: study aim, study design, participant characteristics (sample size, sex, diagnosis), measures used (i.e., how lymphoedema was diagnosed and how adherence was measured) and key findings. Key themes related to adherence were also extracted from the findings of the included articles.

## **Results**

### **Study design**

Detailed information about each study as well as a summary of key findings are reported in Table 2.1. Two of the studies included in the review were qualitative, including one case study (Newman et al., 1996) and one study using semi-structured interviews (James, 2011). Three studies were quantitative, including one quasi-experimental study (Ridner et al., 2008) and two cross-sectional studies (Bani et al., 2007; Ridner et al., 2011).



**Figure 2.1** Review method flow diagram.

## **Participant characteristics**

A total of 957 participants were included across all five studies. Sample sizes for the qualitative studies ranged from one participant (case study) to eight. Sample sizes for the quantitative studies ranged from 51 to 742. One quantitative study (Ridner et al., 2008) and one qualitative study (James, 2011) included both males and females, while the remaining three studies included women with secondary (i.e., breast cancer-related) lymphoedema only. Two samples included individuals with primary lymphoedema (James, 2011; Ridner et al., 2008).

## **Measures**

Lymphoedema diagnosis was conducted at a lymphedema clinic (James, 2011; Newman et al., 1996) or obtained from medical history data (i.e., private health insurance record of being prescribed a specific lymphedema treatment; Ridner et al., 2008). In the remaining studies lymphoedema diagnosis was self-reported (Bani et al., 2007; Ridner et al., 2011). In all of the studies adherence was measured using self-report.

## **Key themes**

There were commonalities across studies in terms of information provision, perceived barriers and symptoms, and the relationships between these factors and adherence.

*Information provision.* For individuals with lymphoedema, information-provision was associated with the use of lymph-drainage massage services (Bani et al., 2007) and lack of knowledge was reported as a barrier to adherence (Ridner et al., 2011).

**Table 2.1** Summary of studies on adherence to lymphoedema self-management recommendations.

Author(s)	Aim	Design	Participants	Measures	Key findings
Newman, Brennan, and Passik (1996)	To illustrate how pain and psychological distress can detract from lymphoedema treatment and quality of life.	Qualitative Case study	Female Secondary lymphoedema (Breast cancer survivor) Age: 55 years	Lymphoedema diagnosis: Diagnosis at a lymphoedema clinic  Adherence: Self-reported use of compression garment and intermittent pneumatic compression device (pump)	Pain was associated with psychological distress and nonadherence.
Bani et al. (2007)	To evaluate the self-reported incidence of lymphoedema in breast cancer survivors and the effect of information provision on the use of lymph-drainage massage services and compression	Cross-sectional	N = 742 Females Secondary lymphoedema (Breast cancer survivors) Age: M = 53.0 ± 11.0 years	Lymphoedema diagnosis: Self-reported  Adherence: Self-reported use of lymph-drainage massage services and compression garments	As a group, participants who were provided with post-operative information were significantly more likely to utilise lymph-drainage massage.

Author(s)	Aim	Design	Participants	Measures	Key findings
	garment use.				
Ridner, McMahon, Dietrich, and Hoy (2008)	To compare treatment adherence and psychological and physical functioning between individuals with primary and secondary (cancer-related) lymphoedema using the Flexitouch <sup>®</sup> system for self-care.	Quasi-experimental Pre- and post-test design	N = 155 (n = 93 secondary lymphoedema; n = 62 primary lymphoedema) Females (n = 134) and males Age group: Mdn = 51-60 years	Lymphoedema diagnosis: Private health insurance record of being prescribed the Flexitouch <sup>®</sup> system for lymphoedema	Individuals with primary lymphoedema reported higher levels of adherence in comparison to individuals with secondary lymphoedema.  No statistically significant association found between adherence and study variables including: age, gender, lymphoedema severity, time since diagnosis, limb volume change and infection.

Author(s)	Aim	Design	Participants	Measures	Key findings
James (2011)	To identify lymphoedema patients' perceived barriers to skin care.	Qualitative Semi-structured interviews	N = 8 Females (n = 5) and males Primary and secondary lymphoedema Age: M = 66.1 ± 11.7 years	Lymphoedema diagnosis: Diagnosis at a lymphoedema treatment clinic Adherence: Self-reported adherence to skin-care recommendations	Fear of the consequences of nonadherence was reported as motivation for adherence. Perceived barriers to adherence include: physical limitations, financial cost and social isolation.
Ridner, Dietrich, and Kidd (2011)	To examine breast cancer-related lymphoedema self-care education, self-care and perceived self-care barriers, burdens and benefits as well as explore the association between education, self-	Cross-sectional	N = 51 Females Secondary lymphoedema (Breast cancer survivors) Age: M = 58 ± 11.3 years	Lymphoedema diagnosis: Self-reported Adherence: Self-reported adherence to lymphoedema self-management recommendations	Perceived barriers to adherence include: lack of time, lack of knowledge, discomfort, lack of visible positive outcome and financial cost. The number of

Author(s)	Aim	Design	Participants	Measures	Key findings
	care, symptoms and quality of life.				<p>lymphoedema symptoms reported was positively associated with the number of self-care behaviours reported.</p> <p>Skin problems were associated with lower levels of adherence to compression therapy.</p>



*Perceived barriers.* Across the included studies, individuals living with lymphoedema reported a number of barriers to adherence, including financial cost (James, 2011; Ridner et al., 2011), reduced physical functioning (James, 2011; Ridner et al., 2011), pain and discomfort (Newman, Brennan, & Passik, 1996; Ridner et al., 2011), time management (Ridner et al., 2011), social isolation (James, 2011), lack of positive outcomes from self-management (Ridner et al., 2011) and psychological distress (Newman et al., 1996).

*Symptoms.* In one study, participants reporting a greater number of symptoms of lymphoedema also reported higher levels of adherence to self-management (Ridner et al., 2011). However, specific symptoms, such as pain (Newman et al., 1996) and skin problems (Ridner et al., 2011), and physical discomfort (Ridner et al., 2011) appear to negatively interfere with adherence.

## **Discussion**

### **Factors associated with adherence to lymphoedema self-management**

The findings from the literature on lymphoedema self-management are limited, with only five studies investigating factors that influence adherence. However, the findings from this scoping review appear to fit with the broader literature base on adherence to chronic disease self-management and adherence to lymphoedema risk minimisation strategies. First, patient knowledge and information provision emerged as two key factors associated with adherence to lymphoedema self-management behaviours (Bani et al., 2007; Ridner et al., 2011). Further support for the importance of patient knowledge for adherence can be found when looking at the at-risk population: Knowledge has also been found to be associated with adherence to preventive

behaviours in breast cancer survivors at risk of developing lymphoedema (Sherman & Koelmeyer, 2011; Sherman et al., 2015).

Second, the barriers reported by individuals living with lymphoedema (i.e., financial cost, physical limitations, negative symptoms, lack of time, social isolation and psychological distress) (James, 2011; Newman et al., 1996; Ridner et al., 2011) are similar to the barriers reported by individuals living with other chronic conditions, such as diabetes, arthritis and asthma (Jerant, von Friederichs-Fitzwater, & Moore, 2005). The next step is to look at which barriers predict nonadherence to lymphoedema self-management guidelines, a question not yet addressed by any identified study. For example, individuals with pain and limited mobility due to lymphoedema may have difficulty donning compression garments and/or performing self-massage. This highlights an important area for future research.

The final common factor found to be related to adherence is symptoms, however, there does not appear to be a direct relationship between the number of symptoms experienced by individuals living with lymphoedema and adherence. In one study (Ridner et al., 2011) symptoms of lymphoedema as a whole were positively associated with adherence, but in the same study skin problems was associated with lower levels of adherence to compression garments. It may be important to consider lymphoedema symptoms individually in terms of their relationship to adherence. Indeed, symptoms such as pain (Newman et al., 1996) and reduced mobility (James, 2011) were reported by individuals living with lymphoedema as barriers to adherence. Other symptoms, such as swelling, may instead motivate individuals to adhere to their self-management regimen. Future research will need to disentangle which symptoms may operate as barriers to adherence and which symptoms motivate individuals to adhere.

## **Limitations of previous research**

**Theory.** The main limitation of previous research on adherence in the lymphoedema context is the lack of a theoretical framework to guide research design and the interpretation of results. None of the studies included in this review mentioned using theory to inform the hypotheses, study design, methodology or data analysis. Future research can benefit from adopting a theoretical framework, such as the social-cognitive and self-regulatory perspective used in previous research in the at-risk population (Sherman & Koelmeyer, 2013; Sherman et al., 2015). The CSM and C-SHIP model both have the potential to help researchers understand the psychological factors underlying adherence to lymphoedema self-management.

**Study design.** Most of the studies included in this review were qualitative or cross-sectional (Bani et al., 2007; James, 2011; Newman et al., 1996; Ridner et al., 2011). As a result, the current knowledge base is too limited to inform the development of tailored intervention strategies to improve adherence. Longitudinal, prospective studies of adherence have the greatest potential for increasing our understanding of adherence to lymphoedema self-management.

**Measure of Adherence.** Another limitation of the studies reviewed is the inconsistencies in how adherence has been measured. There is no known validated measure of adherence to lymphoedema self-management in the literature. All of the studies included in this scoping review used purpose-built measures. In the majority of studies, only a select few self-management behaviours are measured (e.g., wearing compression garments or following a skin care routine) to the exclusion of others (e.g., performing self-lymphatic drainage and monitoring the area of the body for signs of infection). A comprehensive measure that includes all self-management behaviours is needed, similar to the one used by Brown et al. (2014) that might also incorporate self-

care practices for the psychosocial impact of lymphoedema. This will help differentiate between the behaviours with high levels of adherence (e.g., skin care) and behaviours with the lowest levels of adherence (e.g., exercise). For example, individuals may have difficulty initiating and/or maintaining some parts of their self-management regimen more than others. Levels of adherence to skin care may be high because the samples used are primarily female, and skin care practices such as using moisturiser may already be a part of the women's daily routine prior to developing lymphoedema. Other behaviours, such as wearing compression garments, require learning new skills and must be incorporated into their daily or weekly routine. It is important to determine which behaviours to target to improve adherence, and the reasons underlying why individuals may be reporting lower levels of adherence to those behaviours.

**Definition of adherence.** Finally, a clear, consistent definition of adherence is needed moving forward. The studies included in this review defined adherence in one of three ways: (1) in a binary yes/no format (i.e., an individual reported either performing or not performing a behaviour), (2) as intervals of percentage of time (i.e., an individual who reports performing the behaviour greater than 75% of the time is adherent), or (3) as a frequency of performing a behaviour (e.g., daily or once a week). The limitation with defining adherence in a yes/no format is that the degree to which an individual is adherent or nonadherent is not considered. For example, health outcomes for an individual that wears his or her compression garment daily may differ from an individual who wears his or her compression garments most days but not daily; however, both individuals may report adhering to this behaviour. Defining adherence in terms of percentage of time an individual performs the behaviour is limited in that it is a self-reported estimate and may not be accurate. A more useful definition of adherence would be to compare the frequency for which an individual performs a behaviour in

comparison to the prescribed frequency from his or her therapist. Individuals with lymphoedema may receive different recommendations from different therapists (e.g., physiotherapist or massage therapist) and it is important to compare the instructions that patients recall to their reported behaviour to determine whether or not the individual is adherent.

**Limited focus on psychological factors.** So far the focus of previous research has been on managing the swelling associated with lymphoedema only, and not on other symptoms and impacts of the illness. Considering the evidence that lymphoedema has significant, negative psychosocial impacts (Fu et al., 2013), a more holistic view of symptomatology is needed moving forward that includes not only physical symptoms but also psychosocial symptoms and impacts. Future research should measure the physical symptoms of lymphoedema, such as swelling and physical functioning, but also psychological factors such as psychological distress and body image disturbance. This will provide a comprehensive view of the patient experience of living with lymphoedema and can inform the development of interventions for improving quality of life from both a physical and psychosocial perspective. In addition, health professionals should consider providing patients with recommendations for self-management that assist with not only reducing swelling and risk of infection, but also impacts such as psychological distress.

### **Other factors that may underlie adherence to lymphoedema self-management**

One of the purposes of this scoping review was to identify gaps in the knowledge base on adherence to lymphoedema self-management to aid in generating hypotheses to guide future research in this area. Interestingly, no study identified in this review addressed intrapersonal factors which have been found to influence adherence in

other related populations, notably self-regulation, self-efficacy and illness representations. These factors may aid in delineating which factors are instrumental in improving and maintaining adherence to lymphoedema self-management.

**Self-regulation of affect.** The role of an individual's ability to self-regulate affect in adherence has not yet been investigated in individuals with lymphoedema, but it is associated with adherence to preventive behaviours in the at-risk population (Sherman & Koelmeyer, 2013; Sherman et al., 2015). If developing and living with lymphoedema can lead to psychological distress (Chachaj et al., 2010; Fu et al., 2013), and if psychological distress can be a barrier to adherence (DiMatteo et al., 2012; DiMatteo, Lepper, & Croghan, 2000), it logically follows that an individual's ability to self-regulate emotional distress may be related to adherence (de Ridder & Kuijer, 2006). Future research should investigate the relationship between self-regulation of affect and adherence in individuals living with lymphoedema.

**Self-efficacy.** Self-efficacy is a measure of an individual's beliefs in his or her ability to complete certain tasks, for example, self-management behaviours. Self-efficacy shows promise as a key factor for predicting adherence to self-management recommendations in individuals living with lymphoedema. Not only was self-efficacy a significant predictor of adherence in women at risk of developing lymphoedema (Sherman & Koelmeyer, 2013; Sherman et al., 2015), but self-efficacy predicts adherence to a range of self-care and medical regimens, including: physical activity (McAuley et al., 2011), antiretroviral medication (Barclay et al., 2007), diabetes self-management (King et al., 2010) and asthma self-management (Scherer & Bruce, 2001). Therefore, there is strong evidence to support the role of self-efficacy in adherence, and self-efficacy may be another key factor underlying adherence to lymphoedema self-management behaviours.

**Illness representations.** According to the CSM, individuals hold both affective (emotional) and cognitive representations about an illness. Illness representations and their relation to adherence has not yet been investigated in individuals living with lymphoedema, however, research with the at-risk population as well as other chronic conditions provide insight into whether or not they may be important for understanding self-management adherence. Recent reviews of the CSM model (Brandes & Mullan, 2014; Law et al., 2014) found that while illness representations as a whole may not be strongly related to adherence in individuals with chronic illness, illness control beliefs show the strongest relationship to adherence. This is consistent with the finding that the controllability of lymphoedema was associated with adherence to preventive behaviours in breast cancer survivors at risk of developing lymphoedema (Sherman & Koelmeyer, 2013). Other cognitive representations of lymphoedema may also be important: A significant association between perceived consequences and adherence was found for the at-risk population (Sherman & Koelmeyer, 2013). There is also some evidence that emotional illness representations of lymphoedema are related to adherence. One qualitative study in this review that interviewed individuals diagnosed with lymphoedema suggests that a fear of the consequences of nonadherence is a motivating factor to adhere to the skin care regime (James, 2011). It is important to note that emotional illness representations, for example, lymphoedema-specific fear and worry, are distinct from generalised psychological distress (e.g., depression and anxiety). Together, these findings suggest that despite showing weak relationships with adherence in other chronic illnesses, cognitive (i.e., perceived control and perceived consequences) and affective (i.e., fear) illness representations may play a role in understanding lymphoedema self-management.

## **Conclusion**

Living with lymphoedema is associated with a range of negative physical and psychosocial outcomes. Self-management guidelines are an effective way to help manage and prevent the progression of the illness, however, current estimates of levels of adherence amongst individuals with lymphoedema are sub-optimal (Bani et al., 2007; Brown, Cheville, et al., 2014; Rose et al., 1991; Tidhar & Katz-Leurer, 2010). The findings from this scoping review highlight the limited amount of evidence on adherence to lymphoedema self-management and these results have implications for both health professionals and researchers. Patient knowledge and information provision emerged as key factors underlying adherence to lymphoedema self-management, however future research will need to investigate whether or not these findings generalise beyond individuals with breast cancer-related lymphoedema. In addition, previous research has identified a number of potential barriers to adherence, including the financial cost of treatment, social isolation, physical restrictions, lack of time, and psychological distress. Health professionals treating individuals with lymphoedema should be aware of these key factors that may affect adherence to lymphoedema self-management recommendations. Further empirical support is needed before this knowledge can then be used to develop tailored intervention strategies to support individuals at risk of developing lymphoedema and improve level of adherence and patient outcomes. Future research should investigate other psychological factors that may influence adherence to lymphoedema self-management, including self-regulation of affect, self-efficacy, and illness representations.



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### **Chapter 3. Adherence empirical studies**

This chapter is a collection of the empirical studies conducted on adherence to lymphoedema self-management in women with breast cancer-related lymphoedema. The first section of this chapter is an article published in a peer-reviewed journal that discusses the analysis of the baseline data from the main, longitudinal study to determine if specific psychological factors found to be associated with adherence in the at-risk population (i.e., beliefs about the controllability and consequences of lymphoedema, self-efficacy, lymphoedema-related negative affect, self-regulation of negative affect and knowledge about lymphoedema) were also associated with adherence in the affected population. The second section of this chapter covers the main, longitudinal study measured adherence to self-management behaviours and psychological factors (e.g., cognitive and affective illness representations, self-efficacy, self-regulation of negative affect and knowledge about lymphoedema) across three time points (i.e., baseline, six months and 12 months). The third and final section of this chapter is a manuscript currently under review. It describes a cross-sectional study that was conducted to compare the perceived barriers to adherence reported by women affected by breast cancer-related lymphoedema as well as lymphoedema therapists.



### **3.1 Psychosocial factors associated with adherence for self-management behaviors in women with breast cancer-related lymphedema**

This section includes a peer-reviewed journal article published in *Supportive Care Cancer*. This article discusses the baseline data of the main, longitudinal study that were analysed to determine if specific factors found to be associated with adherence in the at-risk population (i.e., beliefs about the controllability and consequences of lymphoedema, self-efficacy, lymphoedema-related negative affect, self-regulation of negative affect and knowledge about lymphoedema) were also associated with adherence in the affected population.

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## Psychosocial factors associated with adherence for self-management behaviors in women with breast cancer-related lymphedema

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### Abstract

**Purpose** Cognitive and affective psychosocial factors have been found to underlie adherence to preventive behaviors in women at risk of developing lymphedema following treatment for breast cancer. The aim of this study was to determine if these factors are associated with adherence to self-management behaviors for women diagnosed with breast cancer-related lymphedema (BCRL).

**Methods** Women with BCRL were recruited through a community-based breast cancer organization and three Australian lymphedema treatment clinics. Participants completed an online questionnaire assessing demographics, medical history, adherence to self-management behaviors, psychosocial variables (personal control, treatment control, consequences, distress, and self-regulation of affect), and knowledge about lymphedema self-management.

**Results** A total of 166 women participated in the study. Participants reported adhering to a mean of five out of seven behaviors, with 19.5 % of participants adhering to all seven behaviors. Adherence to individual behaviors ranged from 65 % (self-lymphatic drainage) to 98.2 % (skin care). Greater knowledge about lymphedema was significantly correlated with higher adherence. Hierarchical multiple linear regression analysis indicated that only medical history factors (time since

diagnosis and having undergone hormone replacement therapy) predicted a significant amount of the variance in adherence.

**Conclusion** These findings highlight the importance of patient knowledge for optimal adherence to a self-management regimen. In addition, medical history factors may identify if a patient is at risk of nonadherence. The lack of association of adherence with other psychosocial factors considered in this study indicates that factors underlying adherence in affected women differ considerably from those factors prompting preventive behavior adherence in the at-risk population.

**Keywords** Breast cancer · Lymphedema · Patient adherence · Self-care · Psychosocial factors

Lymphedema is a chronic illness arising from a malfunction of the lymphatic system that causes a buildup of fluid in an area of the body, most often an arm or a leg [1]. Primary lymphedema is a congenital condition arising from developmental abnormalities [1], whereas secondary lymphedema results from external damage to the lymphatic system, typically from surgery and radiation therapy for cancer [2]. More than 20 % of women diagnosed with invasive breast cancer subsequently develop lymphedema in one or both arms [3]. Living with lymphedema can be physically disabling due to symptoms including swelling, pain, and functional impairment [4]. Lymphedema also impacts negatively on the affected individual from a psychosocial perspective, with impaired quality of life [5–7], body image disturbance [8, 9], and increased psychological distress [5, 8].

The effective self-management of breast cancer-related lymphedema (BCRL) involves numerous behaviors that require on-going enactment for minimizing symptoms and slowing illness progression [10], such as the following: (1)

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wearing a compression garment; (2) performing appropriate exercise type and intensity; (3) practicing good hygiene and skin care; (4) avoiding injury or trauma to the affected area; (5) elevating the affected area to reduce swelling; (6) performing self-lymphatic drainage (massage); and, (7) monitoring the affected area for changes in size, color, and/or temperature [11]. Adherence to lymphedema self-management is critical to avoid further progression of the illness and increased symptom severity [1], which may have negative impacts on an individual's financial (e.g., increased treatment costs) and emotional well-being and quality of life [8].

Despite the importance of lymphedema self-management behaviors, levels of adherence are suboptimal, varying from 28 % [12] to 69 % [13]. Variation between estimates is likely due to differences in specific self-management behaviors measured and how adherence was defined (e.g., the frequency with which a behavior is performed or the proportion of time a patient is adherent) [13, 14]. In order to understand why some individuals are adhering to their self-care and treatment guidelines when others are nonadherent, we need to consider factors (e.g., medical characteristics and beliefs about lymphedema) that may underlie the enactment of these behaviors. In particular, if improving treatment outcomes and relieving symptoms for patients are a priority, it is important to identify which patients are at risk of being poorly adherent in order to intervene early to maximize patient well-being.

Previous research on adherence in BCRL is limited but suggests that a range of psychosocial factors may influence adherence to lymphedema self-management behaviors. For example, psychological distress in women diagnosed with BCRL has been identified as a barrier to adherence [9]. Similarly, amongst women at risk of developing BCRL, a range of cognitive and affective factors are predictive of self-management adherence. In the at-risk group, lower levels of lymphedema-related distress and an increased ability to self-regulate this distress were related to greater adherence [15]. In addition, these women's beliefs in their self-efficacy to follow the recommendations, the controllability of lymphedema, and the negative consequences of lymphedema were predictive of greater adherence [19, 20]. Finally, greater knowledge of risk management behaviors is a strong predictor of adherence in women at risk of BCRL [15–17]. Knowledge has also been associated with adherence in other chronic conditions that, like lymphedema, involve self-management, such as coronary heart disease [18], diabetes [19], and asthma [20]. Considering the similarity between the recommendations provided to women who are at risk of BCRL and the affected population [12], it is likely that these psychosocial factors also underlie adherence to lymphedema self-management behaviors.

These findings are consistent with the views of a broad self-regulation perspective that an individual's behaviors in light of a health threat will be a function of their cognitive and affective representations of that illness [21, 22]. Within the

lymphedema context, this theoretical perspective predicts that for a woman diagnosed with this condition, her adherence to self-management behaviors will be a function of the specific beliefs that she holds about lymphedema (e.g., how effective the self-management behaviors are at controlling lymphedema, her personal ability to carry out the recommended behaviors, and perceived consequences of lymphedema) and her emotional representations (e.g., lymphedema-related distress and worry and her ability to manage any distress).

In sum, despite indications that lymphedema self-management is poorly adhered to, no systematic investigation of cognitive and affective factors and their association with adherence has been undertaken in women diagnosed with BCRL. The aims of this study were to determine whether cognitive and affective factors are associated with lymphedema self-management in individuals diagnosed with BCRL and, particularly, to investigate whether the factors associated with adherence for at-risk populations are also predictive of adherence in affected populations. On this basis, it was predicted that knowledge, self-efficacy, beliefs about the controllability and consequences of lymphedema and lymphedema-related distress, and self-regulatory ability to manage lymphedema-related distress would be associated with adherence.

## Method

### Participants and procedure

English-speaking adult (18+years) women who were previously diagnosed with BCRL were eligible to participate in the study. Following approval from the Macquarie University Human Ethics Review Committee, women were recruited through a community-based breast cancer organization, the Breast Cancer Network Australia, and three lymphedema treatment clinics located in Sydney, Australia. Respondents from the Breast Cancer Network Australia were recruited by email invitation to all breast cancer-affected members interested in research participation. Respondents from the lymphedema clinics were invited directly by clinic therapists who provided the women with an invitational letter that provided the web address to access the online questionnaire.

Participants completed one online questionnaire assessing demographic information, medical history, cognitive and affective factors, and adherence that was estimated to take 20 min to complete.

### Measures

**Demographics and medical history** Demographic information collected included age, Australian Aboriginal or Torres Strait Islander status, education level, income, marital status,

and employment status. Participants provided information about their medical history, including time since lymphedema diagnosis; the type of lymph node surgery that they underwent as part of their breast cancer treatment; and whether or not they received chemotherapy, radiation therapy, and/or hormone replacement therapy as part of their breast cancer treatment.

**Patient adherence** Seven self-management behaviors were chosen based on clinical guidelines [11]. Respondents nominated their specific therapist prescription for lymphedema self-management, as well as their self-reported adherence to these prescribed behaviors. Participants indicated the following: (1) how frequently they were advised to follow each self-management behavior (0=never, 7=daily) and (2) how frequently they currently perform each nominated behavior. To minimize possible bias in responses, the two sets of items were separated by the items assessing illness representations and on separate pages.

Level of adherence was calculated according to the algorithm: score 1 for each recommendation being adhered to at least as often as prescribed and, otherwise, zero. For example, if a participant reported being prescribed self-lymphatic drainage once a week, she was given a score of 1 (i.e., adherent) if she reported performing this behavior once a week or more. If she reported performing this behavior less than once a week, she was given a score of 0 (i.e., nonadherent).

Adherence was calculated for each behavior separately (i.e., a participant was scored as either adherent or nonadherent to each of the seven self-management behaviors) as well as a total sum adherence score out of seven (e.g., a score of 3 indicates that a participant is adherent to three out of the seven self-management behaviors). Each participant was given an adherence score out of seven, even if a woman reported being prescribed less than seven behaviors. For example, if a participant reported that her therapist had not prescribed wearing compression garments and she reported never wearing a garment, she was scored 1 as adherent for that behavior.

**Lymphedema-related cognitions** Beliefs about the controllability and consequences of lymphedema were measured using the personal control (six-item summed score;  $\alpha=0.72$ ), treatment control (five item summed score;  $\alpha=0.79$ ), and perceived consequence (six-item summed score;  $\alpha=0.88$ ) subscales of the Revised Illness Perception Questionnaire (IPQ-R) [23]. The IPQ-R has been validated in a wide range of patient populations, including cancer patients [24]. Items were revised such that “my illness” was replaced with “my lymphedema” (e.g., “My lymphedema is a serious condition”) to ensure that participants were answering with lymphedema in mind and not breast cancer. Each item is rated on a five-point scale (1=strongly disagree, 5=strongly agree). Self-

efficacy was assessed by a single five-point Likert-type item (“I believe that I have the ability to make the necessary lifestyle changes to carry out the recommended self-care practices to manage my lymphedema”) [15, 25].

**Lymphedema-related affect** Lymphedema-related distress was measured using the emotional representation subscale of the IPQ-R (e.g., “When I think about my lymphedema I get upset”) (six-item summed score;  $\alpha=0.84$ ). Self-regulation of negative affect associated with lymphedema was measured using two items [25] (1=strongly disagree, 5=strongly agree): (1) “I believe that I am able to calm myself down when anxious or worried about lymphedema” and “I believe that I am able to limit the amount of stress experienced as a result of lymphedema.” The scores on each item were added to create a sum score for self-regulation of affect ( $\alpha=0.81$ ).

**Knowledge** Knowledge regarding each self-management recommendation was assessed similar to previous lymphedema-related studies [17, 25] using the sum of seven counterbalanced true/false items (1=correct, 0=incorrect).

#### Data analysis

Descriptive statistics were calculated using SPSS<sup>®</sup>, version 21 for the demographic, medical history, and outcome (adherence) variables. Independent samples *t* tests and one-way ANOVAs (categorical variables) and Pearson (continuous variables), Spearman rank (ordinal variables), and point-biserial (dichotomous variables) correlations were undertaken to determine the level of association between the outcome variable (total adherence) and the demographic, medical history, and cognitive and affective variables to identify covariates. A priori calculation of minimum required sample size for multiple regression with seven predictor variables (cognitive and affective variables) was  $N=103$  for a medium effect size of 0.15 and 80 % power.

#### Results

A total of 200 individuals consented to participate in the study, and the final analyzable sample of  $n=166$  remained after removing incomplete data ( $n=34$ ). Sample characteristics are displayed in Table 1. The mean number of behaviors adhered to was 5.3 (SD=1.41) out of 7, with 19.5 % of participants adhering to all seven behaviors. Adherence to individual behaviors ranged from 65 % (performing self-lymphatic drainage) to 98.2 % (practicing good hygiene and skin care) (see Table 2 for descriptive statistics and paired comparisons between mean adherence levels to the self-management behaviors).

**Table 1** Characteristics of study participants ( $n=166$ )

Variable	Mean (SD) or %	Association with total adherence ( $p$ value)
Age (years)	58.04 (10.62)	0.969
Australian Aboriginal or Torres Strait Islander (%)	2	0.482
Education (%)		0.457
High school or less	22.9	
Some university	38.6	
University degree or more	38.5	
Income (%)		0.068
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 (%)		0.227
Married/partnered	79.9	
Divorced/separated	8.3	
Single	7.1	
Widowed	4.1	
Employment status (%)		0.831
Full time	30.8	
Part time	23.7	
Retired	35.5	
Unemployed	10	
Time since lymphedema diagnosis (years)	5.54 (5.49)	0.005*
Type of lymph node surgery (%)		0.562
Sentinel node	10.7	
Axillary	62.7	
I do not know	26.6	
Received chemotherapy (%)	79.9	0.056
Received radiation (%)	76.9	0.472
Received hormone replacement therapy (%)	29.6	0.014*

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

Variables associated at  $p<0.10$  with total adherence were entered into a hierarchical multivariate linear regression model to determine predictors of adherence. Of the demographic and

medical history variables, higher income ( $r=-0.15$ ,  $p=0.068$ ) and a longer time since lymphedema diagnosis ( $r=-0.22$ ,  $p=0.005$ ) were associated with lower levels of adherence, while

**Table 2** Paired samples  $t$  test comparisons between mean adherence levels to the individual self-management behaviors ( $p$  values)

Behavior	1	2	3	4	5	6	7	Adherent $n$ (%)
1. Wear a compression garment.	—	0.682	0.001	0.001	0.190	0.999	0.015	118 (71.1)
2. Perform recommended exercise(s).		—	0.001	0.001	0.372	0.719	0.303	116 (69.9)
3. Practice good hygiene to keep skin and nails clean.			—	0.109	0.001	0.001	0.001	163 (98.2)
4. Actively avoid injury or infection to the affected area.				—	0.001	0.001	0.001	155 (93.4)
5. Perform self-lymphatic drainage (massage).					—	0.205	0.055	108 (65.0)
6. Elevate the affected area.						—	0.502	116 (69.9)
7. Monitor the affected area for changes in color, temperature, or size.							—	120 (71.0)

Due to the number of comparisons made, the critical alpha was reduced to  $p<0.01$



**Table 3** Pearson correlations between the outcome (adherence) variable and psychosocial variables

	1	2	3	4	5	6	7	8	<i>M</i>	<i>SD</i>
1. Adherence		0.155	0.107	0.104	0.050	0.030	-0.154	0.193*	5.30	1.41
2. Personal control			0.266**	0.225**	-0.175*	-0.386**	-0.011	0.060	16.22	2.27
3. Treatment control				0.550**	-0.089	-0.197*	-0.275**	-0.012	16.16	3.32
4. Consequences					-0.158*	-0.291**	-0.023	0.024	15.43	3.27
5. Self-efficacy						0.300**	-0.182*	0.078	4.18	0.73
6. Self-regulation of affect							-0.008	-0.168*	7.69	1.41
7. Distress								-0.157*	15.25	1.95
8. Knowledge									5.51	1.14

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

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

having undergone chemotherapy ( $r=0.15$ ,  $p=0.056$ ) and hormone replacement therapy ( $r=0.20$ ,  $p=0.014$ ) was associated with higher levels of adherence. Pearson's correlations between adherence and the psychosocial variables are displayed in Table 3. Higher knowledge about lymphedema ( $r=0.19$ ,  $p=0.015$ ) and greater beliefs about the personal controllability of lymphedema ( $r=0.16$ ,  $p=0.051$ ) were associated with higher levels of adherence. Higher levels of lymphedema-related distress ( $r=-0.15$ ,  $p=0.052$ ) were associated with lower levels of adherence.

A hierarchical multiple linear regression analysis was conducted. The medical history variables associated with adherence (i.e., income, time since lymphedema diagnosis, chemotherapy, and hormone replacement therapy) were entered on the first step of the model, and the psychosocial predictors (i.e., knowledge, personal control, and distress) were entered on the second step. The overall model was statistically significant ( $R^2=0.16$  (16 %),  $F(7, 145)=4.03$ ,  $p<0.001$ ), with the

medical history variables accounting for approximately 11 % of the variance in the outcome (adherence) variable ( $R^2=0.11$ ). The  $F$  change for the addition of the psychosocial variables was statistically significant ( $F$  change=3.01,  $p=0.032$ ), and the psychosocial variables accounted for an additional 5 % of the variance. In the final model, the only variable significantly associated with reduced adherence was time since lymphedema diagnosis ( $t=-2.06$ ,  $p=0.042$ ) and, for increased adherence, hormone replacement therapy ( $t=2.41$ ,  $p=0.017$ ). A summary of the results of the regression analysis is shown in Table 4.

## Discussion

This study aimed to determine whether cognitive and affective factors are associated with lymphedema self-management in individuals diagnosed with BCRL and, particularly, whether

**Table 4** Hierarchical multiple linear regression analysis to determine factors associated with adherence to lymphedema self-management strategies

		Unstandardized coefficients		Standardized coefficients	<i>t</i>	<i>p</i> value	95.0 % CI
		<i>B</i>	Std. error	Beta			
Step 1	Income	-0.16	0.09	-0.14	-1.78	0.077	(-0.35, 0.02)
	Time since diagnosis	-0.05	0.02	-0.21	-2.64	0.009	(-0.09, -0.01)
	Chemotherapy	0.39	0.27	0.11	1.43	0.154	(-0.15, 0.92)
	Hormone replacement therapy	0.50	0.20	0.19	2.47	0.015	(0.10, 0.89)
Step 2	Income	-0.14	0.09	-1.2	-1.55	0.123	(-0.33, 0.04)
	Time since diagnosis	-0.04	0.02	-0.17	-2.06	0.042	(-0.08, -0.01)
	Chemotherapy	0.53	0.27	0.15	1.97	0.051	(-0.01, 1.06)
	Hormone replacement therapy	0.49	0.20	0.19	2.41	0.017	(0.09, 0.89)
	Knowledge	0.15	0.10	0.12	1.51	0.132	(-0.04, 0.34)
	Personal control	0.08	0.05	0.13	1.70	0.092	(-0.01, 0.18)
	Distress	-0.09	0.06	-0.13	-1.67	0.098	(-0.20, 0.02)

$R^2=0.07$  for step 1;  $\Delta R^2=0.05$ ,  $p=0.037$  for step 2

*CI* confidence interval

the factors associated with adherence for at-risk populations are also predictive of adherence in affected populations. Adopting a broad self-regulation framework [21, 22] and guided by previous research on the at-risk population [15–17, 25], it was predicted that knowledge, self-efficacy, beliefs about the controllability and consequences of lymphedema and lymphedema-related distress, and self-regulatory ability to manage lymphedema-related distress would be associated with adherence. Overall, women in this study reported adhering to a mean of five out of seven self-management behaviors; however, only 19.5 % of women reported adhering to all seven behaviors (i.e., 100 % adherent). Two previous studies reported levels of adherence similar to this study [13, 14], whereas others have found lower levels of adherence (<30 %) [12, 26]. Inconsistent findings may be a result of differences in how adherence was measured and defined. This study addressed some of the limitations of earlier work [12, 14, 26] investigating adherence to lymphedema self-management by calculating a total adherence score tailored to each woman's specific self-management prescription. Measuring adherence as a direct function of the prescribed behaviors provides a more accurate estimation of adherence in these populations. Inconsistent findings from previous studies might also be explained by the finding that levels of adherence vary amongst the individual self-management behaviors. For example, in this study, adherence to self-lymphatic massage and compression garment use was relatively low, consistent with previous research [12, 13, 26]. In comparison, adherence to skin hygiene and avoiding injury was significantly greater than all other behaviors. This finding is also similar to previous research with both the affected [13, 14] and at-risk [15, 17] populations. Skin care, such as applying moisturizer, is a commonly undertaken daily behavior for women generally and, therefore, is likely to have been part of the participants' regular routine prior to developing lymphedema [17]. However, for other behaviors such as compression garment use and self-lymphatic drainage, the women would have had to learn new skills as well as be able to incorporate this new behavior into their daily or weekly routine. Compression garment use is one of the more challenging ongoing self-management strategies [12, 13, 26], and the relatively low level of adherence reported in this study is consistent with this view.

The results of this study suggest that medical history variables are important for understanding adherence to lymphedema self-management. Time since diagnosis and hormone replacement therapy use both explained a significant portion of the variance in adherence in the regression model. These findings are in contrast to a previous study that found no relationship between demographic and medical history variables and adherence to a home-based lymphedema treatment system [27]. However, it is plausible that patients are initially more enthusiastic about, and committed to, their self-management but become less adherent over time as they face barriers to

following their regime (e.g., a lack of time). Furthermore, a recent study [28] found that adherence to health checks (e.g., mammograms) was associated with hormone replacement therapy use.

Regarding our hypothesis, the multivariate analyses provided limited support for the self-regulation perspective that a range of cognitive and affective variables would be associated with self-management adherence [21, 22]. Although greater knowledge about lymphedema self-management was significantly correlated with higher levels of adherence, it was not a significant predictor of adherence in the regression model. Similarly, beliefs about the personal controllability of lymphedema and lymphedema-related distress were included in the model but did not predict a significant amount of the variance.

That knowledge was significantly associated with adherence is consistent with findings from both the at-risk population and other chronic disease populations. Knowledge about lymphedema [16, 17, 25] and information provision [29] is associated with adherence to lymphedema preventive behaviors in the at-risk population. For chronic disease management more generally, knowledge is associated with adherence to lifestyle changes for individuals living with coronary heart disease [18] and the self-management of diabetes [19]. Collectively, these findings support the critical importance of a patient having adequate knowledge about his or her illness and self-management for optimal adherence. Thus, lymphedema therapists and other practitioners should aim to assess patients' level of knowledge about lymphedema at initial diagnostic assessment and provide adequate information and resources, such as access to relevant websites.

This study's findings have implications for the self-regulation perspective used as a framework for this research [21, 22]. Although the findings from the at-risk population are in support of these theories, it may be that cognitive and affective factors are not as significant for understanding adherence in populations affected by chronic disease. For example, a meta-analysis found that the cognitive and affective illness representations are poor predictors of adherence for individuals with chronic diseases, such as asthma, diabetes, and hypertension [30]. Similarly, a systematic review found that only belief about the controllability of illness is associated with adherence to self-management in children and young adults with chronic disease [31]. Perhaps, self-regulatory models are more effective at predicting individuals' responses to health threats in comparison to predicting adherence to disease self-management.

That the cognitive and affective variables were not significant predictors of adherence in this study is inconsistent with previous findings from the at-risk population. This suggests that different processes impact on the at risk compared to the affected groups and that women with breast cancer at risk of developing lymphedema may not be an informative

comparison group for understanding adherence to lymphedema self-management behaviors, despite the similarity between recommendations provided to both groups and their similar medical histories. It may be that the threat of developing an illness motivated adherence differently to the reality of living with, and self-managing, a chronic disease; however, to the best of our knowledge, no other study has compared a population at risk of developing a disease and a population diagnosed with the disease on factors underlying patient adherence.

For future research in the lymphedema context, it may be more informative to look at other chronic illnesses that involve self-management regimes instead of the at-risk population. For example, diabetes may be a useful comparator for the lymphedema context as the diabetes self-care regimen is similar to lymphedema self-care in a number of ways, including skin care, exercise, and compression garment use [19, 32]. Another potential line of investigation is to determine if the barriers reported by individuals living with lymphedema are actual predictors of adherence. Previous research has identified a number of reported barriers including the financial cost of treatment [9, 33], physical limitations and/or symptoms [9, 33, 34], time management [9, 35], social isolation [33], and psychological distress [34]. These barriers are similar to those reported by individuals living with other chronic illnesses that require on-going self-management, such as diabetes, asthma, and arthritis [36].

When interpreting the findings of this study, some possible limitations need to be considered. First, the data were obtained from self-report only, and there was no objective measure of lymphedema diagnosis nor stage or severity. To overcome this limitation, indicators of lymphedema status were included, such as number of symptoms and time since diagnosis. Second, data were collected using an online survey and participants were recruited from a community-based breast cancer organization. Participants in this sample are well educated, with a higher proportion of participants in this sample having attained the equivalent of a Bachelor degree or higher (38 %) in comparison to the average for Australian women (27 %) [37]. This sample may also be more actively concerned about their health than other women in the target population. Finally, it is possible that we did not find significant associations between psychosocial variables and adherence due to methodological limitations in how the variables were measured. For example, self-efficacy has been found to be a key factor associated with adherence not only amongst women at risk of developing BCRL [15, 25], but also more broadly when looking at medication compliance [38], adherence to lifestyle changes (e.g., exercise) [39], and adherence to self-management (e.g., diabetes) [40]. The item used to measure self-efficacy in this study was used in previous studies with the at-risk population [15, 25], but perhaps, it was not sensitive enough to capture a relationship between self-efficacy and lymphedema self-management.

In conclusion, this study found that adherence to BCRL self-management is not optimal, with only approximately one in five women reporting 100 % adherence to their self-management regime. The findings of this study suggest that medical characteristics are important for identifying women who are at risk of nonadherence. Furthermore, knowledge about lymphedema self-management is associated with adherence, and so, lymphedema therapists should aim to assess knowledge at initial diagnostic assessment. Finally, the psychosocial factors associated with adherence in women at risk of BCRL as identified in previous research were not found to be significantly associated with adherence in women diagnosed with BCRL in this study.

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**Conflict of interest** The authors have full control over primary data and allow the journal to review this primary data if requested. The authors would like to report no conflict of interest.

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### **3.2 Adherence to lymphoedema self-management does not follow**

#### **common sense**

Lymphoedema is a chronic, progressive condition characterised by swelling that occurs when protein-rich fluid accumulates in the affected area of the body (Bernas, 2013; Ridner, 2013). Secondary lymphoedema is a common consequence of cancer treatment that involves surgical removal of lymph nodes (Bernas, 2013; Ridner, 2013) or damage to the lymphatic system resulting from radiation therapy (Bernas, 2013; Ridner, 2013; Shah & Vicini, 2011) and possibly chemotherapy (Cariati et al., 2015; Norman et al., 2010; Ridner, 2013). Approximately one in five women treated for breast cancer will develop lymphoedema, with incidence rates higher for those who have undergone more extensive surgery (i.e., axillary-lymph node dissection in comparison to sentinel-node biopsy, greater number of lymph nodes removed) and who are overweight or obese (DiSipio, Rye, Newman, & Hayes, 2013). Women with breast cancer-related lymphoedema may experience severe swelling, pain and reduced physical functioning (Hayes et al., 2011).

The self-management of breast cancer-related lymphoedema includes consistently following a regimen of practices that helps maintain treatment outcomes over the long-term, including wearing compression garments, self-lymphatic drainage, therapeutic exercises, skin and nail care, elevation, avoiding injury or trauma to the affected area and monitoring the affected area for skin changes and signs of infection (Merchant & Chen, 2015; NLN, 2011). Despite the importance of self-management, previous research suggests that adherence levels are suboptimal, varying from 13% to 79%, depending on the particular behaviour (Alcorso, Sherman, Koelmeyer, Mackie, & Boyages, 2015; Bani et al., 2007; Brown, Cheville, Tchou, Harris, & Schmitz, 2014;

Ridner, McMahon, Dietrich, & Hoy, 2008; Rose, Taylor, & Twycross, 1991; Tidhar & Katz-Leurer, 2010). For example, adherence to skin care is typically high (70-98.2%)(Alcorso et al., 2015; Brown et al., 2014), whereas fewer women are adherent to the recommended exercises (14-70%) (Alcorso et al., 2015; Brown et al., 2014; Tidhar & Katz-Leurer, 2010).

Previous research on adherence to lymphoedema self-management is scarce, hence there is limited evidence to suggest what factors might underlie nonadherence. This study's hypotheses were informed by social cognitive theories of health behaviour, including the Common Sense Model (CSM) of illness self-regulation (Diefenbach & Leventhal, 1996; Leventhal, Meyer, & Nerenz, 1980) and the Cognitive-Social Health Information Processing (C-SHIP) theory (Miller & Diefenbach, 1998), as well as previous research in the at-risk population of breast cancer survivors. The CSM and C-SHIP models propose that individuals form representations (CSM) or encodings (C-SHIP) of an illness that consist of cognitive beliefs (e.g., beliefs about the consequences or controllability of an illness) as well as emotional (affective) responses to illness (e.g., fear, anger or worry about an illness) (Diefenbach & Leventhal, 1996; Leventhal et al., 1980; Miller & Diefenbach, 1998; Miller, Shoda, & Hurley, 1996). These cognitive and affective factors are said to be associated with health behaviours, a view supported by studies investigating the relationships between specific illness representations and adherence to chronic illness self-management. For example, a systematic review of 15 studies assessing CSM illness representations in children and adolescents (Law, Tolgyesi, & Howard, 2014), and a meta-analysis of 30 studies assessing the CSM in adults (Brandes & Mullan, 2014), found that greater beliefs about the controllability of an illness are strongly related to higher levels of adherence to chronic illness self-management (e.g., diabetes, asthma, renal disease). There is also some, albeit mixed,

evidence suggesting that lower illness-related negative affect (Law et al., 2014), greater beliefs about the negative consequences of an illness (Law et al., 2014), and greater illness coherence (i.e., the extent to which an individual believes he or she understands their illness) (Brandes & Mullan, 2014) are related to self-management adherence for illnesses including diabetes, hypertension and asthma. However, other illness representations, such as beliefs about the causes, identity (i.e., symptoms) and timeline (i.e., chronic/acute) are at best weakly associated with self-management adherence (Brandes & Mullan, 2014; Law et al., 2014).

Cognitive and affective factors in the lymphoedema context have been investigated in women regarded as being at-risk of developing breast cancer-related lymphoedema. These women are given a set of preventive guidelines to follow to minimise the risk of developing lymphoedema (risk-management strategies) (Bani et al., 2007). The preventive guidelines are similar to that recommended for lymphoedema self-management for affected women (e.g., avoiding injury or trauma to the arm or affected area; Bani et al., 2007). Cognitive illness representations have been associated with adherence to risk-management behaviours in women at-risk. Specifically, greater beliefs in the controllability of lymphoedema (Sherman & Koelmeyer, 2013) and self-efficacy to perform risk-management strategies (Sherman & Koelmeyer, 2013; Sherman, Miller, Roussi, & Taylor, 2015) are associated with greater adherence, whereas greater beliefs in the negative consequences of lymphoedema are associated with lower adherence (Sherman & Koelmeyer, 2013). Affective factors are also important for understanding risk-management behaviours in this population: lower illness-related negative affect (Sherman et al., 2015) as well as greater beliefs about one's ability to self-regulate negative affect (Sherman & Koelmeyer, 2013; Sherman et al., 2015) have been associated with adherence.

Contrary to the findings in the at-risk population, the limited evidence in women with breast cancer-related lymphoedema (Alcorso et al., 2015) suggests that only knowledge and beliefs about the personal controllability of lymphoedema are weakly associated with adherence. Beliefs about the negative consequences of lymphoedema, the effectiveness of treatment for controlling lymphoedema, self-efficacy and the ability to regulate negative affect related to lymphoedema were not associated with adherence in this population. These preliminary findings suggest that cognitive and affective factors may not be strong factors underlying adherence to self-management in women affected with breast cancer-related lymphoedema. However, these cross-sectional data precluded any investigation of how changes in cognitive and affective factors may impact adherence over time. Moreover, the researchers adopted a flawed approach to analysing adherence, using a total score reflecting combined adherence across seven different self-management behaviours (e.g., skin care, compression garment use, exercise, etc.), rather than considering adherence to each behaviour separately. Given that adherence varies across the different recommended behaviours (e.g., 70-98.2% for skin care versus 14-70% for exercise; Alcorso et al., 2015; Brown et al., 2014; Tidhar & Katz-Leurer, 2010), it is possible that cognitive and affective factors may be predictors of adherence to some, but not all, of the recommended behaviours.

The aim of this study was to determine whether cognitive and affective factors predict changes in adherence to self-management practices over time in women with breast cancer-related lymphoedema. Based on previous research in affected (Alcorso et al., 2015) and at-risk (Sherman & Koelmeyer, 2013; Sherman et al., 2015) populations, and other chronic illness contexts (Brandes & Mullan, 2014; Law et al., 2014), it was predicted that knowledge, self-efficacy, beliefs about the controllability and



consequences of lymphoedema and lymphoedema-related distress, and self-regulatory ability to manage lymphoedema-related distress would be predictors of adherence.

## **Method**

### **Participants and procedure**

English-speaking adult (18+years) women who were previously diagnosed with breast cancer-related lymphoedema were eligible to participate in the study. Following approval from the Macquarie University Human Ethics Review Committee, women were recruited through a community-based breast cancer organisation, the Breast Cancer Network Australia, and three lymphoedema treatment clinics located in Sydney, Australia. Respondents from the Breast Cancer Network Australia (BCNA) were recruited by email invitation that was sent to approximately 2000 breast cancer-affected members interested in research participation. It is not possible to know with certainty how many of the women in the general pool from the BCNA were affected with breast cancer-related lymphoedema. However, approximately 20% of all women with invasive breast cancer subsequently develop lymphoedema (DiSipio et al., 2013); therefore, we anticipated that up to 400 of the BCNA research pool members would have been affected with lymphoedema. On this basis, the 170 women recruited from the BCNA research pool represent an estimated 43% response rate. Respondents from the lymphoedema clinics ( $n = 30$ ; response rate 28.8%) were invited directly by clinic therapists through an invitational letter that provided the web address to access the online questionnaire. Participants completed three online questionnaires (baseline, 6- and 12-months) assessing demographic information and medical history (at baseline only), cognitive and affective factors, and adherence. Each questionnaire was estimated to take 20 min to complete and participants received a \$5 coffee voucher for each

follow-up questionnaire completed (maximum \$10 compensation for completing all three questionnaires).

## **Measures**

**Patient adherence.** Seven self-management behaviours were chosen based on clinical guidelines (National Lymphedema Network, 2011): wearing a compression garment, performing recommended exercise(s), skin care, avoiding injury or trauma to the affected area, self-lymphatic drainage, elevating the affected area and monitoring the affected area for changes. Participants nominated their specific therapist prescription for lymphoedema self-management, as well as their self-reported adherence to these prescribed behaviours including how frequently they: (1) were advised to follow each self-management behaviour (0=never, 7=daily) and (2) currently performed each nominated behaviour.

Level of adherence was calculated according to the following algorithm: score 1 for each recommendation being adhered to at least as often as prescribed and, otherwise, zero. For example, if a participant reported being prescribed self-lymphatic drainage once a week, she was given a score of 1 (i.e., adherent) if she reported performing this behaviour at least once a week. If she reported performing this behaviour less than once a week, she was given a score of 0 (i.e., nonadherent).

Adherence was calculated for each behaviour separately (i.e., a participant was scored as either adherent or non-adherent to each of the seven self-management behaviours) as well as a total sum adherence score out of seven (e.g., a score of three indicates adherence to three out of the seven self-management behaviours). Each participant was given an adherence score out of seven, even if she reported being prescribed less than seven behaviours. For example, if a participant reported that her

therapist had not prescribed wearing compression garments and she reported never wearing a garment, she was scored 1 as being adherent for that behaviour.

**Lymphoedema-related cognitions.** Beliefs about the controllability, consequences and coherence of lymphoedema were measured using the personal control (six-item summed score;  $\alpha = 0.72$ ), treatment control (five item summed score;  $\alpha = 0.79$ ), perceived consequences (six-item summed score;  $\alpha = 0.88$ ) and coherence (five item summed score;  $\alpha = 0.90$ ) subscales of the Revised Illness Perception Questionnaire (IPQ-R) (Moss-Morris et al., 2002). The IPQ-R has been validated in a wide range of patient populations, including cancer patients (Ashley et al., 2013). Items were revised such that “my illness” was replaced with “my lymphoedema” to ensure that participants were answering with lymphoedema in mind and not breast cancer. Self-efficacy was assessed by a single item (“I believe that I have the ability to make the necessary lifestyle changes to carry out the recommended self-care practices to manage my lymphoedema”) (Sherman & Koelmeyer, 2013; Sherman et al., 2015). Each item was rated on a 5-point Likert-type scale (1=strongly disagree, 5=strongly agree).

**Lymphoedema-related affect.** Lymphoedema-related distress was measured using the emotional representation subscale of the IPQ-R (e.g., “When I think about my lymphoedema I get upset”) (6-item summed score;  $\alpha = 0.84$ ). Self-regulation of negative affect associated with lymphoedema was measured using two items: (1) “I believe that I am able to calm myself down when anxious to limit the amount of stress experienced as a result of lymphoedema”; and, (2) “I believe that I am able to limit the amount of stress experienced as a result of lymphoedema” (Sherman & Koelmeyer, 2013; Sherman et al., 2015). The scores on each item were added to create a summed score for self-regulation of affect ( $\alpha = 0.81$ ). All items were rated on a 5-point Likert-type scale (1=strongly disagree, 5=strongly agree).

**Knowledge.** Knowledge regarding each self-management recommendation was assessed similar to previous lymphoedema-related studies (Sherman & Koelmeyer, 2013; Sherman et al., 2015) using the sum of seven counterbalanced true/false items (1=correct, 0=incorrect).

**Demographics, medical history and health economic variables.** Demographic information collected included age, Australian Aboriginal or Torres Strait Islander status, education level, income, marital status, and employment status. Participants provided information about their medical history including details about their breast cancer treatment (i.e., lymph node surgery type, chemotherapy, radiation therapy and hormone replacement therapy), lymphoedema (i.e., time since diagnosis, stage, current treatment, symptoms), and whether or not they have any comorbid conditions. Health economic variables measured included whether or not the participant received subsidised treatment (i.e., by having an Enhanced Primary Care plan or compression garment subsidy scheme), if she had private health insurance, and an estimation of her annual out-of-pocket costs for lymphoedema treatment.

## **Data analysis**

**Descriptive statistics and identifying covariates.** Descriptive statistics were calculated for participant demographic, medical history and health economic characteristics. Independent samples *t*-tests and chi-square analyses were conducted on baseline characteristics to compare participants in the final sample with participants lost to follow-up. Independent samples *t*-tests and one-way ANOVAs (categorical variables) and Pearson (continuous variables), Spearman rank (ordinal variables), and point-biserial (dichotomous variables) correlations were undertaken to determine the level of association between the outcome variables (adherence to lymphoedema self-

management behaviours) and the demographic, medical history and health economic variables at baseline to identify potential covariates. Variables associated with adherence behaviours at  $p < 0.100$  were included as covariates in subsequent analyses.

**Change in adherence over time and predictors of adherence.** Maximum-likelihood linear mixed models were used to determine: (1) if adherence to each lymphoedema self-management behaviour changed over time and (2) if cognitive and affective variables predicted adherence to self-management behaviours at each assessment point. A linear mixed models approach was chosen due to its flexibility and power for analysing longitudinal data (Avilés, 2001). Linear mixed models are particularly useful for maximizing the number of data points included in an analysis for datasets with missing values. Furthermore, mixed models provide a reliable estimate of change in variables over time by accounting for variability among participants over time (Avilés, 2001). Data analyses accounted for both time-varying and subject-based (i.e., measured at baseline only) variables. Fixed effects included time and identified covariates. Random effects for a participant-specific random intercept accounted for within-participant correlation.

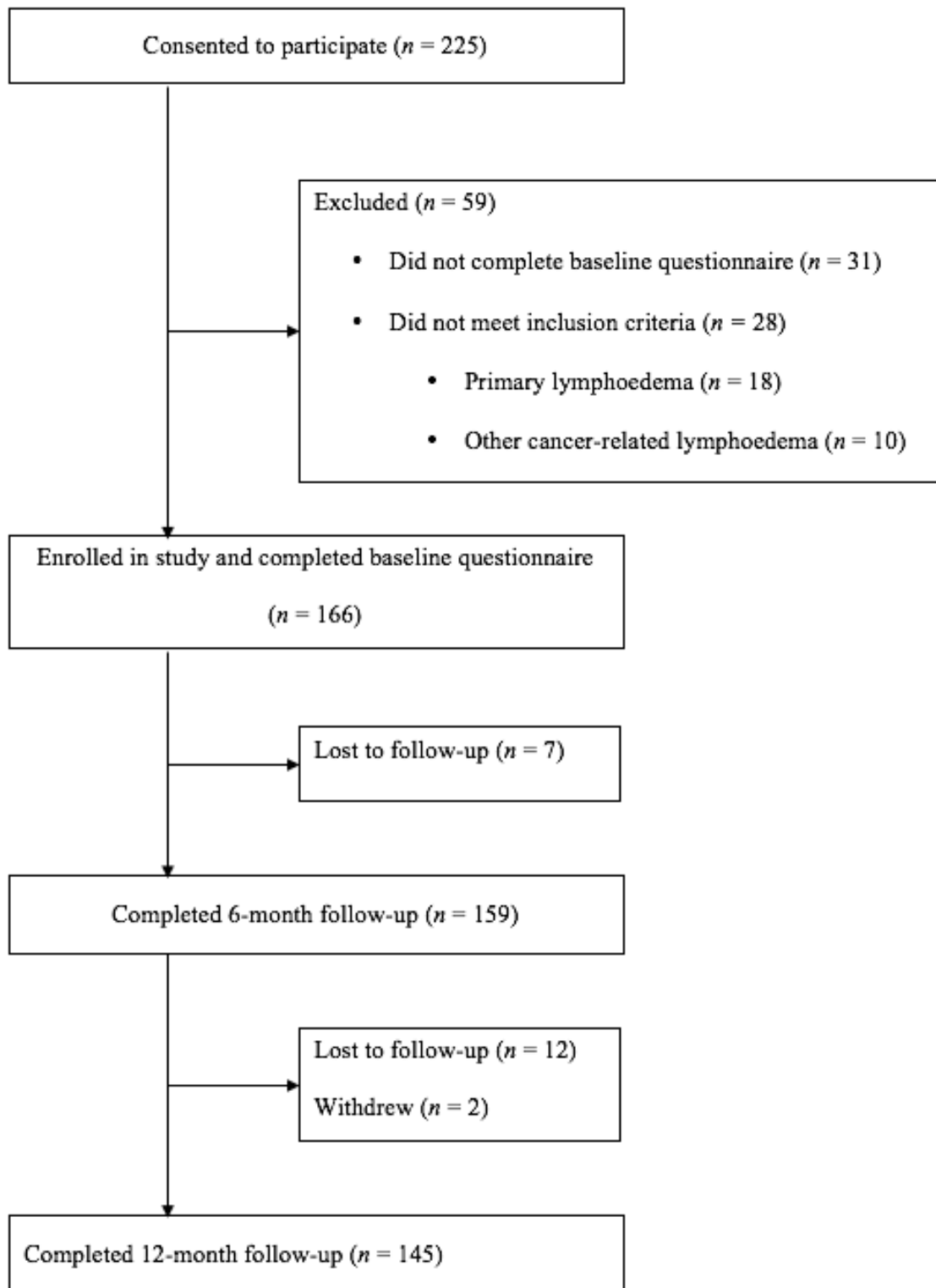
First, separate analyses were undertaken to determine if total adherence and/or adherence to each individual self-management behaviour changed over time. Next, each cognitive and affective variable was tested as a predictor of adherence behaviours that changed over time. The critical  $p$  value for the predictor variables was reduced from 0.05 to 0.006 to adjust for the multiple analyses (eight predictor variables) in accordance with the Bonferonni correction method. All analyses were carried out using SPSS (Version 21, Armonk, NY: IBM Corp).

## Results

A total of 200 individuals consented to participate in the study, and the final analysable sample of  $n = 166$  remained at baseline after removing incomplete data ( $n = 34$ ). Figure 3.2 displays participant progress throughout the study. Following the baseline questionnaire data collection, seven participants at 6-months and 14 participants at 12-months were lost to follow-up, leaving 145 participants who completed all three questionnaires (87.3% retention). Participant baseline characteristics and between-subject comparisons for participants that completed all three questionnaires (final sample) and individuals lost to follow-up are displayed in Table 3.2.1. The group of participants in the final sample and the group of participants lost to follow-up were similar across all characteristics except employment status,  $\chi^2 = (3, N = 166) = 17.40, p = .015$ , with more participants in the final sample being employed part-time in comparison to full-time.

### **Change in adherence to lymphoedema self-management over time.**

Adherence to each self-management behaviour as well as total adherence at baseline, 6-months and 12-months is reported in Table 3.2.2. Adherence to exercise changed over time,  $F(2,290) = 5.25, p = 0.006$ , decreasing from 69.9% at baseline to 52.2% at 6-months ( $p = 0.004$ ). This decrease in exercise was sustained at 12-months, with no change from 6- to 12-months. Adherence to self-lymphatic drainage also changed over time,  $F(2,290) = 3.15, p = 0.006$ , with a decrease from 65% at baseline to 50.3% at 12 months ( $p = 0.017$ ). There was no difference in adherence from baseline to 6-months, or 6- to 12-months. Total adherence (scored out of seven) did not change over time; therefore, analyses were undertaken to identify cognitive and affective factors predicting change in adherence to specifically exercise and self-lymphatic drainage.



**Figure 3.2** Participant progress through each phase of the study.

**Identifying covariates.** Bivariate correlations between adherence to exercise and self-lymphatic drainage and demographic, medical history and health economic variables are displayed in Table 3.2.3. For exercise, receiving hormone replacement therapy was associated with adherence ( $r = 0.19, p = 0.022$ ), whereas having a comorbid condition was associated with nonadherence ( $r = -0.14, p = 0.083$ ). For self-lymphatic drainage, receiving radiation therapy ( $r = 0.16, p = 0.048$ ) and subsidised treatment (i.e., an Enhanced Primary Care plan) ( $r = 0.15, p = 0.066$ ) were associated with adherence, whereas higher income was associated with nonadherence ( $r = -0.14, p = 0.095$ ). Therefore, these variables were subsequently controlled for in the analyses to determine predictors of adherence to exercise and self-lymphatic drainage.

**Change in cognitive and affective variables over time.** Descriptive statistics for the cognitive and affective variables at baseline, 6-months and 12-months are displayed in Table 3.2.4. Number of symptoms significantly changed over time,  $F(2, 288) = 11.16, p < 0.001$ , increasing from baseline ( $M = 5.23, SD = 2.41$ ) to 6-months ( $M = 5.81, SD = 2.81; p = 0.002$ ), and then decreasing from 6- to 12-months ( $M = 4.98, SD = 2.53; p < 0.001$ ). Beliefs about the personal controllability of lymphoedema changed significantly over time,  $F(2, 286) = 293.86, p < 0.001$ , increasing from baseline ( $M = 16.26, SD = 2.27$ ) to 6-months ( $M = 19.94, SD = 1.77; p < 0.001$ ) and from 6- to 12-months ( $M = 23.6, SD = 3.78; p < 0.001$ ). Beliefs about the negative consequences of lymphoedema significantly changed over time,  $F(2, 284) = 129.36, p < 0.001$ , increasing from baseline ( $M = 15.46, SD = 3.22$ ) to 6-months ( $M = 17.12, SD = 3.38; p < 0.001$ ), and from 6- to 12-months ( $M = 18.79, SD = 4.31; p < 0.001$ ).

Beliefs about the coherence of lymphoedema significantly changed over time,  $F(2, 290) = 250.99, p < 0.001$ , increasing from baseline ( $M = 10.59, SD = 4.21$ ) to 6-



**Table 3.2.1** Participant characteristics at baseline.

Variable	Final sample	Withdrew / lost to follow-up	Between group comparisons <i>t</i> or $\chi^2$ , <i>p</i>
	<i>n</i> = 145 <i>M</i> ( <i>SD</i> ) or %	<i>n</i> = 21 <i>M</i> ( <i>SD</i> ) or %	
Age (years)	57.41 (9.29)	58.67 (11.83)	$t(166) = 0.56, p = .576$
Australian Aboriginal or Torres Strait Islander (%)	1.4	14.3	
Education (%)			$\chi^2 = (2, N = 166) = 9.56, p = .215$
High school or less	20.4	42.9	
Some tertiary	42.2	28.6	
Tertiary degree or more	37.4	28.5	
Income (%)			$\chi^2 = (3, N = 166) = 7.58, p = .751$
Less than \$50,000	29.1	31.3	
\$50,001 - \$100,000	39.6	43.7	
\$100,001 – \$150,000	20.1	12.5	
More than \$150,000	11.2	12.5	
Marital status (%)			$\chi^2 = (3, N = 166) = 3.55, p = .470$
Married/partnered	81.5	76.2	
Divorced/separated	8.9	4.8	

Variable	Withdrew / lost to		Between group comparisons <i>t</i> or $\chi^2, p$
	Final sample	follow-up	
	<i>n</i> = 145 <i>M</i> ( <i>SD</i> ) or %	<i>n</i> = 21 <i>M</i> ( <i>SD</i> ) or %	
Single	6.2	9.5	
Widowed	3.4	9.5	
Employment status (%)			$\chi^2 = (3, N = 166) = 17.40, p = .015$
Full time	28.3	47.6	
Part time	25.5	9.5	
Retired	34.5	42.9	
Unemployed	11.7	0.0	
Type of lymph node surgery (%)			$\chi^2 = (1, N = 166) = 1.06, p = .588$
Sentinel node	10.2	14.3	
Axillary	63.9	52.4	
I do not know	25.9	33.3	
Received chemotherapy (%)	78.2	90.5	$\chi^2 = (1, N = 166) = 1.71, p = .191$
Received radiation (%)	76.9	76.2	$\chi^2 = (1, N = 166) = 0.01, p = .945$
Received hormone replacement therapy (%)	29.3	28.6	$\chi^2 = (1, N = 166) = 0.01, p = .945$
Time since lymphoedema diagnosis (years)	5.61 (5.61)	5.24 (4.77)	$t(166) = -0.29, p = .777$
Lymphoedema Stage (%)			$\chi^2 = (4, N = 166) = 7.54, p = .110$

Variable	Withdrew / lost to		Between group comparisons <i>t</i> or $\chi^2, p$
	Final sample	follow-up	
	<i>n</i> = 145 <i>M</i> ( <i>SD</i> ) or %	<i>n</i> = 21 <i>M</i> ( <i>SD</i> ) or %	
Stage 0 (Subclinical)	20.3	0.0	
Stage 1 (Mild)	56.6	73.6	
Stage 2 (Moderate)	21.7	21.1	
Stage 3 (Severe)	0.7	5.3	
I do not know	0.7	0.0	
Lymphoedema treatment (%)			
Bandaging	25.2	42.9	$\chi^2 = (1, N = 166) = 2.89, p = .089$
Manual lymphatic drainage	70.7	61.9	$\chi^2 = (1, N = 166) = 0.68, p = .410$
Surgery	0.0	0.0	
Laser	7.6	9.5	$\chi^2 = (1, N = 166) = 0.31, p = .575$
Number of lymphoedema symptoms	5.22 (2.40)	4.67 (2.52)	$t(166) = -0.99, p = .323$
Comorbid chronic conditions(s) (%)			
Diabetes Type 1	0.7	0.0	$\chi^2 = (1, N = 166) = 0.15, p = .696$
Diabetes Type 2	3.6	0.0	$\chi^2 = (1, N = 166) = 0.79, p = .375$
Coronary heart disease	1.4	4.8	$\chi^2 = (1, N = 166) = 1.08, p = .299$
Stroke	0.0	0.0	

Variable	Withdrew / lost to		
	Final sample	follow-up	Between group comparisons
	<i>n</i> = 145	<i>n</i> = 21	
	<i>M</i> ( <i>SD</i> ) or %	<i>M</i> ( <i>SD</i> ) or %	<i>t</i> or $\chi^2$ , <i>p</i>
Asthma	16.7	4.8	$\chi^2 = (1, N = 166) = 2.02, p = .156$
Chronic Obstructive Pulmonary Disease	0.0	0.0	
Chronic Kidney Disease	0.7	0.0	$\chi^2 = (1, N = 166) = 0.15, p = .696$
None	81.2	81.0	$\chi^2 = (1, N = 166) = 0.01, p = .982$
Enhanced Primary Care Plan (%)	24.6	42.1	$\chi^2 = (1, N = 166) = 2.6, p = .272$
Private Health Insurance (%)	59.4	73.7	$\chi^2 = (1, N = 166) = 1.44, p = .487$
Compression garment subsidy scheme (%)	18.1	21.1	$\chi^2 = (1, N = 166) = 0.49, p = .782$
Out of pocket lymphoedema treatment costs (%)			$\chi^2 = (4, N = 166) = 2.84, p = .829$
\$0 - \$500	55.7	73.2	
\$501 - \$1,000	20.7	6.7	
\$1,001 - \$1,500	9.6	6.7	
\$1,501 - \$2,000	8.1	6.7	
More than \$2,000	5.9	6.7	

months ( $M = 15.15$ ,  $SD = 2.22$ ;  $p < 0.001$ ) and from 6- to 12-months ( $M = 19.71$ ,  $SD = 4.05$ ;  $p < 0.001$ ). Finally, knowledge about lymphoedema self-management significantly changed over time,  $F(2, 434) = 5.82$ ,  $p = 0.005$ , increasing from 6- ( $M = 5.42$ ,  $SD = 1.10$ ) to 12-months ( $M = 5.81$ ,  $SD = 1.07$ ;  $p = 0.003$ ).

**Cognitive and affective predictors of adherence.** All cognitive and affective predictor variables and the identified covariates were assessed to determine if they were associated with adherence to either exercise and/or self-lymphatic drainage (Table 3.2.4). None of the predictors were significantly associated with adherence to either exercise or self-lymphatic drainage. A non-significant trend was evident for greater beliefs about self-efficacy being associated with adherence to exercise,  $F(1,371) = 3.12$ ,  $p = 0.078$  and for number of symptoms and self-lymphatic drainage,  $F(1,332) = 3.15$ ,  $p = 0.077$ .

## Discussion

This study is the first to measure illness representations over time in women with breast cancer-related lymphoedema. We also measured adherence to lymphoedema self-management behaviours to determine if cognitive and affective factors are significant predictors of adherence. Overall, adherence to self-management varied across the seven behaviours measured. At the 12-month follow-up, adherence remained high (>80% of women adherent) for skin care, avoiding injury and monitoring the affected area and moderate (approximately 60-70) for wearing compression garments and elevating the affected area. In contrast, levels of adherence for exercise (51.7%) and self-lymphatic drainage (50.3%) were relatively low in comparison to the other behaviours. Furthermore, although total adherence was stable over time, adherence significantly decreased over time for exercise and self-lymphatic drainage. These



**Table 3.2.2** Adherence to lymphoedema self-management behaviours.

Self-management behaviour	Baseline ( <i>n</i> = 166)			6 months ( <i>n</i> = 159)			12 months ( <i>n</i> = 145)			Change over time?
	Adherent	Freq.	%	Adherent	Freq.	%	Adherent	Freq.	%	<i>F</i> , <i>p</i> -value
Wear a compression garment.	No	48	28.9	No	47	29.6	No	44	30.3	0.41, 0.662
	Yes	118	71.1	Yes	112	70.4	Yes	101	69.7	
Perform recommended exercise(s).	No	50	30.1	No	76	47.8	No	70	48.3	5.25, 0.006
	Yes	116	69.9	Yes	83	52.2	Yes	75	51.7	
Practice good hygiene to keep skin and nails clean.	No	3	1.8	No	9	5.7	No	6	4.1	0.77, 0.926
	Yes	163	98.2	Yes	150	94.3	Yes	139	95.9	
Actively avoid injury or infection to the affected area.	No	11	6.6	No	13	8.2	No	5	3.4	2.3, 0.101
	Yes	155	93.4	Yes	146	91.8	Yes	140	96.6	
Perform self-lymphatic drainage (massage).	No	58	35.0	No	73	45.9	No	72	49.7	3.15, 0.045
	Yes	108	65.0	Yes	86	54.1	Yes	73	50.3	
Elevate the affected area.	No	50	30.1	No	49	30.8	No	53	36.6	1.24, 0.292
	Yes	116	69.9	Yes	110	69.2	Yes	92	63.4	
Monitor the affected area for changes in colour, temperature or size.	No	46	29.0	No	38	23.9	No	28	19.3	1.76, 0.173
	Yes	120	71.0	Yes	121	76.1	Yes	117	80.7	
<b>Total adherence <i>M</i> (<i>SD</i>)</b>	5.30 (1.39)			5.12 (1.52)			5.08 (1.47)			1.27, 0.282





findings are partially consistent with a previous study (Brown et al., 2014) that found that adherence to self-management behaviours, except self-lymphatic drainage, was stable over 12-months. Health professionals should be aware that women with breast cancer-related lymphoedema may be less likely to follow recommendations for exercise and self-lymphatic drainage over time. Follow-up appointments may be an opportunity to check-in with women to see if they are still following recommendations for these behaviours, and to remind them of the importance of adherence to maintain treatment outcomes and slow the progression of lymphoedema. One possible explanation for suboptimal adherence is that there has been recent changes to clinical guidelines for lymphedema self-management, and the majority of self-management behaviours (compression, self-monitoring, skin care, infection management and self-lymphatic drainage massage) have not yet been established as effective by peer-reviewed studies (Ridner et al., 2012; Ridner, Qui, Kayal, Kang & Fu, 2014). The lack of consensus for evidence-based clinical guidelines may lead to confusion and lower beliefs in the perceived effectiveness of self-management strategies amongst women with breast cancer-related lymphoedema.

There were a few significant changes in the cognitive variables over time. Beliefs about the personal controllability of lymphoedema, the negative consequences of lymphoedema and the coherence of lymphoedema significantly increased over time. Furthermore, knowledge about lymphoedema self-management increased over time. It is possible that the women in this study became more interested and involved in their own self-management as a function of completing the study questionnaires, and that this engagement with the study affected their illness beliefs at each follow-up. It is also possible that the participants discussed the issues addressed by the questionnaires with their lymphoedema therapists.



**Table 3.2.3** Pearson (continuous variables), Spearman rank (ordinal variables), and point-biserial (dichotomous variables) correlations between the outcome variables (adherence to exercise and self-lymphatic drainage) and the demographic, medical history and health economic variables at baseline.

Variable	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15
1. Exercise	—	0.15*	-0.01	0.08	0.06	0.03	0.03	0.19**	0.02	0.01	-0.14*	-0.04	0.02	-0.04	-0.05
2. Self-lymphatic drainage		—	0.09	-0.10	-0.14*	0.04	0.16**	0.12	-0.09	0.08	-0.13	0.15*	0.03	-0.13	-0.13
3. Age			—	-0.16*	0.33*	-0.10	0.19**	-0.08	0.29***	0.02	0.01	0.11	-0.02	-0.02	-0.20**
4. Education				—	0.26***	-0.01	0.01	0.05	0.24***	-0.09	-0.05	-0.02	0.10	-0.03	0.12
5. Income					—	-0.01	0.04	-0.02	0.02	-0.02	-0.17**	-0.13	0.03	0.12	0.07
6. Chemotherapy						—	-0.01	-0.15*	-0.05	0.06	-0.12	-0.09	-0.08	-0.14*	-0.02
7. Radiation therapy							—	0.07	-0.04	0.16**	0.04	-0.13	0.05	0.01	-0.03
8. HRT								—	-0.11	0.11	0.19**	-0.02	-0.07	-0.07	0.13
9. Time since diagnosis									—	-0.01	-0.07	-0.05	-0.02	-0.07	-0.01
10. Stage of lymphoedema										—	0.03	0.03	-0.05	0.13	0.20**
11. Comorbid condition											—	0.20**	0.11	0.02	0.13
12. EPC plan												—	0.05	0.13	0.08
13. PHI													—	-0.01	0.19**
14. Compression subsidy														—	-0.01
15. Out of pocket costs															—

Note: HRT = Hormone replacement therapy; EPC = Enhanced Primary Care; PHI = Private health insurance.

\*  $p < 0.10$ , \*\*  $p < 0.05$ , \*\*\*  $p < 0.01$



Contrary to prediction and previous research in the at-risk population (Sherman & Koelmeyer, 2013; Sherman et al., 2015), none of the cognitive and affective variables were significant predictors of adherence to either exercise or self-lymphatic drainage. It is worth noting, however, that there was a non-significant trend for greater beliefs about self-efficacy predicting adherence to exercise. This trend is consistent with findings in the at-risk population (self-efficacy is associated with adherence to risk-management strategies; Sherman & Koelmeyer, 2013; Sherman, Miller, Roussi, & Taylor, 2015) as well as in individuals living with diabetes (i.e., self-efficacy is associated with adherence to self- management; King et al., 2010; Walker, Gebregziabher, Martin-Harris, & Egede, 2015). The self-management of diabetes and lymphoedema overlap for several behaviours, including wearing compression garments, performing exercise(s) and practicing good hygiene and skin care (Cullum, Nelson, Fletcher, & Sheldon, 2001), and so diabetes may be a useful comparison group for lymphoedema.

The findings of this study have implications for the social cognitive theories of health behaviour used as a framework for this research, namely the CSM (Diefenbach & Leventhal, 1996) and C-SHIP model (Miller & Diefenbach, 1998). Although a previous systematic review (Law et al., 2014) and meta-analysis (Brandes & Mullan, 2014) found relationships between illness representations (i.e., beliefs about the controllability of an illness, beliefs about the consequences of an illness and illness-related negative affect) and adherence to self-management across multiple chronic illness types (e.g., diabetes, asthma and renal disease), these relationships are weak with low effect sizes (e.g., -0.02 – 0.12; Brandes & Mullan, 2014). It may be that cognitive and affective factors are more relevant for predicting individuals' responses to a health threat, such as breast cancer survivors' adherence to risk-management strategies when faced with the threat of developing lymphoedema, in comparison to predicting adherence to chronic



**Table 3.2.4** Descriptive statistics and change over time for the predictor variables.

Variable	Range	Baseline <i>M (SD)</i>	6 Months <i>M (SD)</i>	12 Months <i>M (SD)</i>	Change over time		Predictive of adherence to exercise?		Predictive of adherence to self- lymphatic drainage?	
					<i>F</i>	<i>p</i>	<i>F</i>	<i>p</i>	<i>F</i>	<i>p</i>
Symptoms	0 – 10	5.23 (2.41)	5.81 (2.81)	4.98 (2.53)	11.16	<0.001	0.81	0.370	3.15	0.077
Personal control	6 – 30	16.26 (2.27)	19.94 (1.77)	23.60 (3.78)	293.86	<0.001	0.13	0.718	0.08	0.783
Treatment control	5 – 25	16.24 (3.21)	16.34 (1.94)	16.54 (3.17)	0.55	0.580	0.18	0.672	0.04	0.843
Consequences	6 – 30	15.46 (3.22)	17.12 (3.38)	18.79 (4.31)	129.36	<0.001	1.94	0.166	0.90	0.345
Coherence	5 – 30	10.59 (4.21)	15.15 (2.22)	19.71 (4.05)	251.00	<0.001	0.01	0.976	0.80	0.373
Self-efficacy	1 – 5	4.14 (0.74)	4.22 (0.64)	4.09 (0.77)	1.95	0.145	3.12	0.078	0.70	0.404
Self-regulation of affect	2 – 10	7.71 (1.42)	7.54 (1.74)	7.78 (1.55)	1.85	0.159	2.02	0.156	0.93	0.336
Lymphoedema-related distress	6 – 30	15.24 (1.97)	16.04 (5.02)	15.82 (5.18)	1.77	0.172	1.58	0.210	0.10	0.748

disease self-management. In addition, it may be that cognitive and affective factors are more important for predicting individuals' distress and coping responses related to a chronic illness (Hagger & Orbell, 2003), rather than adherence behaviour. Indeed, previous research in women with breast cancer-related lymphoedema found that cognitive and affective factors are associated with depression, anxiety and stress (Alcorso & Sherman, 2015).

Medical history variables seem to be important for understanding both total adherence to self-management (Alcorso et al., 2015) as well as adherence to individual self-management behaviours. Breast cancer treatment factors in particular appear to be relevant to adherence: receiving hormone replacement therapy was significantly associated with adherence to exercise and receiving radiation therapy was significantly associated with adherence to self-lymphatic drainage. Although one previous study found that adherence to a home-based treatment system was not related to medical history factors for individuals with primary (non-cancer related) or secondary (cancer-related) lymphoedema (Ridner et al., 2008), adherence to health checks (e.g., mammograms) was found to be associated with hormone replacement therapy use (Byles, Leigh, Chojenta, & Loxton, 2014). It is possible that women receiving hormone replacement therapy may be more concerned about their health and taking an active role in managing their health because of a concern about the potential negative side effects associated with this treatment (e.g., increased cancer risk)(Chlebowski & Anderson, 2012). It may be useful for health professionals to keep these breast cancer treatment-related factors in mind to help identify women who may be at risk of nonadherence to self-management.

There are a few limitations to keep in mind when interpreting the results of this study. First, the sample of women with breast cancer-related lymphoedema was



heterogeneous in terms of medical characteristics. The women varied considerably in length of time since diagnosis, ranging from one year to over ten years of living with lymphoedema. Previous research in the at-risk population that found relationships between cognitive and affective factors and adherence included women within the first year post-breast cancer treatment (Sherman & Koelmeyer, 2013; Sherman et al., 2015). It is possible that cognitive and affective factors are more important for understanding adherence behaviour in the early stages of being at-risk or being diagnosed with a chronic illness like lymphoedema. Furthermore, women in this study also varied in the severity of their lymphoedema, with the majority reporting subclinical or mild lymphoedema. Women that have experienced none or few symptoms of lymphoedema may not believe that it is important to adhere to self-management recommendations. Self-management may be perceived to be more relevant for women in the later stages of lymphoedema who experience obvious symptoms including severe swelling, pain and physical limitations. A second key limitation of this study is that all adherence was self-reported. It may improve the accuracy of measuring adherence to have a partner or family member report how frequently their loved one performs each self-management behaviour. Finally, this study's sample was predominantly recruited from members of a consumer-based breast cancer organisation that explicitly expressed interest in participating in breast cancer-related research. As a result, this sample of women with breast cancer-related lymphoedema are likely to be highly motivated to participate in research and highly experienced with completing online surveys.

In conclusion, nonadherence to self-management behaviours is suboptimal amongst women with breast cancer-related lymphoedema, especially for exercise and self-lymphatic drainage. Cognitive and affective variables may not be relevant for predicting adherence in this population, however, medical history, such as receiving

hormone replacement therapy and radiation therapy for breast cancer are associated with adherence to exercise and self-lymphatic drainage, respectively. Future research should investigate whether or not there are factors other than cognitive and affective variables that predict adherence to breast cancer-related lymphoedema self-management. Other factors not measured in this study that have been found to be related to adherence in other illnesses include women's motivation to adhere (or lack thereof) and the role of social support provided by family and friends (DiMatteo, Haskard-Zolnierek, & Martin, 2012). In addition, it may be useful to study women who are successfully adhering to their self-management regimen to determine what facilitates their adherence. Future qualitative research may provide insight into the practical strategies affected women use to adhere to self-management behaviours (DiMatteo et al., 2012).

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### **3.3 Perceived barriers to adherence to breast cancer-related lymphoedema self-management**

This section includes a manuscript that has been submitted for publication to the Journal of Lymphoedema and is currently under review. This manuscript describes a cross-sectional study that was undertaken to identify the perceptions of lymphoedema therapists and women affected by breast cancer-related lymphoedema about barriers to adherence to self-management. Lymphoedema therapists' and affected women's ratings were compared for seven potential barriers to adherence, including concerns about appearance, physical limitations, financial cost, time limitations, lack of social support, access to treatment and lack of information.

The research in this section has been presented at the *World Congress of Lymphology*, San Francisco, 2015 and at an invited seminar presentation at the *Macquarie University Lymphoedema Seminar*, Sydney, 2015.



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

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## **Abstract**

**Background:** Self-management is critical for the effective maintenance of breast-cancer related lymphoedema, but levels of adherence are suboptimal.

**Aims:** The aim of this study was to compare the perceptions of lymphoedema therapists with those of women affected with this condition regarding barriers to self-management.

**Methods:** Women with breast cancer-related lymphoedema ( $N = 162$ ) were recruited through a community-based breast cancer organisation and lymphoedema clinics.

Lymphoedema therapists ( $N = 98$ ) were recruited through an online registry.

Participants completed an online survey assessing perceived barriers to adherence to lymphoedema self-management, demographic information, medical history (affected women), and lymphoedema therapy practice details (therapists).

**Results:** MANOVA 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.

**Conclusions:** Differences between affected women and therapists in beliefs about barriers to lymphoedema self-management suggest a need for improvements in patient-provider communication.

**Declaration of Interest:** None.

**Keywords:** lymphoedema, patient adherence, self-management, breast cancer

**Key points:**

- Despite the importance of ongoing lymphoedema self-management behaviours for maintaining treatment outcomes and slowing illness progression, current estimates indicate suboptimal adherence amongst women with breast cancer-related lymphoedema.
- This study investigated potential perceived barriers to self-management adherence and compared perceived barriers reported by women affected by breast cancer-related lymphoedema as well as lymphoedema therapists (i.e., physiotherapists, massage therapists, occupational therapists and registered nurses).
- A statistically significant difference was found between affected women's and therapists' ratings of perceived barriers to self-management adherence such that therapists were more likely to agree that each of seven potential barriers (i.e., concerns about appearance, physical limitations, financial cost, time limitations, lack of social support, access to treatment, lack of information) negatively impacted adherence, while affected women were more likely to disagree that these factors negatively impacted their adherence to self-management behaviours.

Breast cancer-related lymphoedema is a chronic illness caused by a malfunction of the lymphatic system resulting from surgery and radiation therapy (Ridner, 2013). More than 20% of women diagnosed with invasive breast cancer subsequently develop lymphoedema, often in their chest, breast or arm (DiSipio, Rye, Newman, & Hayes, 2013). Breast cancer-related lymphoedema is a growing problem: As breast cancer incidence rates and survival rates increase (Australian Institute of Health and Welfare, 2012), more women will be diagnosed with this chronic illness. Living with lymphoedema can be physically disabling due to symptoms including swelling, pain, discomfort, functional impairment and numbness (Fu & Rosedale, 2009). Lymphoedema also impacts negatively on the affected individual from a psychosocial perspective, with women commonly reporting impaired quality of life (Mak et al., 2009; Tsuchiya, Horn, & Ingham, 2008), body image disturbance (Fu et al., 2013; Rhoten, Radina, Adair, Sinclair, & Ridner, 2015; Ridner, Bonner, Deng, & Sinclair, 2012; Teo, Novy, Chang, Cox, & Fingeret, 2015), difficulties with employment (Fu, 2008), negative changes to relationships and sexuality (Radina, Watson, & Faubert, 2008) and psychological distress (Fu et al., 2013). Women with breast cancer-related lymphoedema can receive treatment from a lymphoedema therapist (i.e., registered nurse, physiotherapist, occupational therapist or massage therapist) to reduce lymphatic fluid build-up in the affected area. Common treatments include therapist-assisted lymphatic drainage, bandaging, and pneumatic compression (Ridner, 2013). Lymphoedema therapists also prescribe a self-management regimen for the affected woman in order to maintain treatment outcomes and slow illness progression (Johnstone, Hawkins, & Hood, 2006).

Lymphoedema self-management may involve a variety of behaviours including: wearing a compression garment; practicing 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, color 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), hence, adherence to a self-management regime is critical for optimal treatment outcomes. Despite the importance of lymphoedema self-management, research suggests that adherence levels are suboptimal. Studies measuring adherence to self-management behaviours in women with breast-cancer related lymphoedema have reported levels ranging from 13% to 79%, depending on the particular behaviour (Alcorso, Sherman, Koelmeyer, Mackie, & Boyages, 2015; Bani et al., 2007; Brown, Cheville, Tchou, Harris, & Schmitz, 2014; Ridner, McMahon, Dietrich, & Hoy, 2008; Rose, Taylor, & Twycross, 1991; Tidhar & Katz-Leurer, 2010). For example, adherence to skin care is typically high (70-98.2%)(Alcorso et al., 2015; Brown et al., 2014), whereas fewer women are adherent to the recommended exercises (14-70%) (Alcorso et al., 2015; Brown et al., 2014; Tidhar & Katz-Leurer, 2010).

In order to improve levels of adherence, it is important to understand factors influencing self-management behaviour. Several theories of health behaviour (Bandura, 1998; Rosenstock, 1974) include perceived barriers as a key factor that determines performance of the target behaviour, in this case lymphoedema self-management behaviour. For example, the Health Belief Model (HBM) (Rosenstock, 1974) proposes that barriers is one of the four factors influencing health behaviour, with a meta-analysis finding that barriers was one of the strongest predictors of health behaviour in this model (Carpenter, 2010). Barriers are also included in Social Cognitive Theory (SCT) (Bandura, 1998), which distinguishes between personal barriers that influence beliefs



about self-efficacy (e.g., an individual's beliefs about whether or not he or she is able to perform the target health behaviour) and health resource barriers (e.g., access to medical care). It is important 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 individuals with lymphoedema have been operationalised with a lymphoedema-specific exercise barriers self-efficacy scale. These barriers include concerns about appearance, experiencing symptoms of lymphoedema, fear of lymphoedema progression, and lack of knowledge about exercise (Buchan, Janda, Box, Rogers, & Hayes, 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 (e.g., of compression garments) (James, 2011; Ridner, Dietrich, & Kidd, 2011), physical limitations (James, 2011; Ridner et al., 2011), lack of time (Radina, Armer, & Stewart, 2014; Ridner et al., 2011), limited social support (James, 2011) and insufficient knowledge (Ridner et al., 2011). These are similar to the barriers reported by individuals living with other chronic conditions that involve a self-management regime, such as diabetes, arthritis and asthma (Jerant, von Friederichs-Fitzwater, & Moore, 2005).

In addition to the barriers reported in qualitative research, there are two factors that may prevent women from following their self-management regime. Individuals living with lymphoedema report that compression garments are uncomfortable and unattractive to wear (Lam, Wallace, Burbidge, Franks, & Moffatt, 2006; Pyszel, Malyszczak, Pyszel, Andrzejak, & Szuba, 2006; Ridner et al., 2012), and so concerns about their appearance may prevent women from wearing their compression garment.

Women living with breast cancer-related lymphoedema have also reported difficulty accessing treatment (Barlow et al., 2014). If a woman has difficulty accessing a lymphoedema therapist for treatment she may not have adequate knowledge about how to undertake self-management of her condition. Moreover, lack of access to a therapist may mean that an individual affected with lymphoedema does not have a prescribed self-management regime that is regularly monitored by a trained therapist. In sum, previous research suggests that women with breast cancer-related lymphoedema face a number of barriers to self-management, but these have not been investigated using a quantitative approach.

A second gap in the literature that this study addresses is that no known study has compared the perceptions of women with breast cancer-related lymphoedema and of lymphoedema therapists regarding barriers to self-management regime adherence. 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 patient-related than health care system-related barriers to colorectal cancer screening, and that both groups agreed that lack of awareness, lack of knowledge, and lack of provider 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 screening 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 perceptions of lymphoedema therapists and their patients may differ 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 self-management adherence. Based on previous research, we hypothesised that there would be significant differences between the extent to which affected women and therapists agreed that each barrier negatively impacted self-management adherence.

## **Methods**

### **Participants and procedure**

**Women with breast cancer-related lymphoedema.** 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 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. Approximately 2000 women are registered members of the BCNA research pool. It is not known specifically how many of these women have been diagnosed with lymphoedema. However, approximately 20% of all women with a diagnosis of invasive breast cancer develop lymphoedema (DiSipio et al., 2013); therefore, we anticipate that up to 400 of the BCNA research pool members may have been affected with lymphoedema. On this basis, the 170 women recruited from the BCNA research pool represent an estimated 43% response rate. Participants from the lymphoedema 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 the online patient information and

consent form. In total, 200 women affected with lymphoedema responded to the online study survey. After providing consent online, participants continued on to complete the study questionnaire that was estimated to take 20 minutes.

**Lymphoedema therapists.** Lymphoedema therapists were recruited through the Australasian Lymphology Association's (ALA) National Lymphoedema Practitioners Register (NLPR) which is a public register of lymphoedema therapists, including registered nurses, physiotherapists, occupational therapists and massage therapists, located in Australia and New Zealand. Therapists that included an e-mail address in their listing were sent an e-mail invitation to participate in the study ( $n = 146$ ; response rate 82.2%). E-mail invitations provided the web address to access 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.

## Measures

**Perceived barriers to adherence.** Both affected women and therapists were asked to indicate how strongly they agreed or disagreed with each of seven barriers to self-management adherence: 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 (Radina et al., 2014; Ridner et al., 2011), lack of social support (James, 2011), access to treatment (Barlow et al., 2014) and lack of information (Ridner et al., 2011). Each perceived barrier was measured using a 5-point Likert-type scale (0 = strongly disagree, 5 = strongly agree).

**Sample characteristics.** Demographic information collected from women with breast cancer-related lymphoedema 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 (state) and how long they have been treating individuals living with lymphoedema.

**Data analysis.** Descriptive statistics were calculated for participant characteristics and perceived barriers to adherence. All statistical analyses were conducted using SPSS<sup>®</sup>, 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 self-management adherence. Post-hoc 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 breast cancer-related lymphoedema consented to participate in the study and the final analyzable sample of  $n = 162$  remained after removing incomplete data ( $n = 38$ ). Sample characteristics for affected women are displayed in Table 3.3.1. A total of 120 therapists consented to participate in the study and the final analyzable sample of  $n = 98$  remained after removing incomplete data ( $n = 22$ ). Lymphoedema therapist sample characteristics are displayed in Table 3.3.2.

**Table 3.3.1** Affected women with breast cancer-related lymphedema sample characteristics ( $n = 162$ ).

<b>Variable</b>	<b>Mean (SD) or %</b>
Age (years)	57.33 (10.13)
Australian Aboriginal or Torres Strait Islander (%)	2
<i>Education (%)</i>	
High school or less	22.2
Some tertiary	38.3
Tertiary degree or more	39.5
<i>Income (%)</i>	
Less than \$50,000	35.8
\$50,000 - \$100,000	32.1
\$100,000 - \$150,000	21.6
More than \$150,000	10.4
<i>Marital status (%)</i>	
Married/Partnered	80.2
Divorced/Separated	9.3
Single	7.4
Widowed	3.1
<i>Employment status (%)</i>	
Full-time	29.6
Part-time	24.1
Retired	36.4
Unemployed	9.9
<i>Type of LN Surgery (%)</i>	
Sentinel node	12.8
Axillary	78.8
I don't know	8.3

Variable	Mean (SD) or %
Received Chemotherapy (%)	77.8
Received Radiation (%)	79.6
Received HRT (%)	41.4
Time since lymphedema diagnosis (years)	5.12 (7.15)
<i>Lymphedema severity (%)</i>	
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, HRT = Hormone replacement therapy

**Table 3.3.2** Lymphedema therapist sample characteristics ( $n = 98$ ).

<b>Variable</b>	<b>Mean (SD) or %</b>
<i>Occupation (%)</i>	
Physiotherapist	49
Massage Therapist	29
Occupational Therapist	13
Registered Nurse	9
Years treating individuals with lymphedema	9.42 (6.04)
<i>Practice location within Australia - State (%)</i>	
New South Wales	29
Queensland	20
Victoria	17
South Australia	9
Western Australia	9
Australian Capital Territory	3
Northern Territory	3
Tasmania	0



**Table 3.3.3** Univariate between-subjects comparisons for perceived barriers to lymphedema self-management adherence (1 = strongly disagree, 5 = strongly agree).

<b>Barrier to adherence</b>	<b>Affected women</b>	<b>Therapists</b>	<i>F</i> (1, 257)	<i>p</i>	Partial $\eta^2$
	( <i>n</i> = 162)	( <i>n</i> = 98)			
	<i>M</i> ( <i>SD</i> )	<i>M</i> ( <i>SD</i> )			
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	< .001	.54
2. Physical limitations or pain/discomfort prevent women from performing some or all of the self-care recommendations (e.g., wearing a compression garment or self-lymphatic massage).	1.91 (0.83)	3.83 (0.89)	304.87	< .001	.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	< .001	.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	< .001	.40
5. A lack of social support (e.g., 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	< .001	.64
6. Women have difficulty locating and/or traveling to a	1.94 (0.92)	3.94 (0.88)	307.19	< .001	.54

	Affected women ( <i>n</i> = 162)	Therapists ( <i>n</i> = 98)			
Barrier to adherence	<i>M</i> ( <i>SD</i> )	<i>M</i> ( <i>SD</i> )	<i>F</i> (1, 257)	<i>p</i>	Partial $\eta^2$
lymphedema clinic or lymphedema therapist for treatment.					
7. Women require more information in order to properly manage their lymphedema.	2.05 (0.80)	4.23 (0.78)	454.62	< .001	.64



## **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 negatively impacts adherence, while affected women were more likely to disagree that it negatively impacts adherence (Table 3.3.3).

## **Discussion**

This is the first study to directly compare the beliefs of women with breast cancer-related lymphoedema with those of lymphoedema therapists regarding perceived barriers to self-management adherence. As predicted, there was a significant difference between groups on the extent to which they agreed that each barrier negatively influences adherence. For each of seven statements about potential barriers to adherence (i.e., 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 are salient barriers to adherence. In contrast, affected women were more likely to disagree that each potential barrier influenced adherence. This finding suggests that there is a disconnect 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.

The finding that, overall, affected women disagreed that each potential barrier influenced their adherence conflicts with previous findings from qualitative research. Previously, women have reported that financial cost (e.g., of compression garments)

(James, 2011; Ridner et al., 2011), physical limitations (James, 2011; Ridner et al., 2011), a lack of time (Radina et al., 2014; Ridner et al., 2011), limited social support (James, 2011) and insufficient knowledge (Ridner et al., 2011) prevented them from following their self-management regime. 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 breast cancer-related lymphoedema. In addition, only one of these studies was conducted in Australia (James, 2011) with the other studies being located in the United States (Radina et al., 2014; Ridner et al., 2011). It is possible that the inconsistent findings reflect differences in culture and/or health care systems between these two countries. Finally, there may be other, more critical barriers to adherence faced by women with breast cancer-related lymphoedema 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 not something that they feel is a concern for them. Although previous research has found suboptimal levels of adherence to self-management in women with breast cancer-related lymphoedema (Alcorso et al., 2015; Brown et al., 2014), 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 successful in the self-management of 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 have had few symptoms of lymphoedema at the time of completing the survey, and as such, the questions about barriers to adherence may have been less salient for these women.

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 breast cancer-related lymphoedema, although they were informed by prior qualitative work in this area (Barlow et al., 2014; James, 2011; Lam et al., 2006; Pyszel et al., 2006; Radina et al., 2014; Ridner et al., 2012, 2011). 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 generalizability of findings. Only women with breast cancer-related lymphoedema were included, and so the results may not extend to individuals with lymphoedema related to other types of cancer or primary lymphoedema.

## **Conclusions**

In conclusion, differences were found between affected women's and therapists' ratings of perceived barriers to self-management adherence. Therapists were more likely to agree that each of seven potential barriers (i.e., concerns about appearance, physical limitations, financial cost, time limitations, lack of social support, access to treatment, lack of information) negatively impacted adherence, while affected women were more likely to disagree that these factors negatively impacted their adherence to self-management behaviours. Since adherence to self-management is critical for maintaining treatment outcomes and slowing the progression of lymphoedema (Ridner, 2013), future research should investigate whether interventions targeting patient-provider communication are beneficial for increasing adherence to lymphoedema self-

management. Future research should also aim to identify what women with breast cancer-related lymphoedema 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 breast cancer-related lymphoedema (e.g., 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. Health 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 patient-provider communication may have benefits for increasing adherence to lymphoedema self-management. Indeed, patient-provider communication has been found to related to adherence to diabetes self-management (Heisler, Bouknight, Hayward, Smith, & Kerr, 2002), which is similar to lymphoedema self-management in a number of ways, including skin care, exercise and compression garment use (Bains & Egede, 2011; Cullum, Nelson, Fletcher, & Sheldon, 2001).

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## **Part 2. Distress**

The research in the second part of this thesis addresses the second aim: to identify cognitive and affective predictors of psychological distress in women with breast cancer-related lymphoedema. This part consists of two chapters. The first chapter (Chapter 4) is a literature review that examines previous research on psychological distress in women with breast cancer-related lymphoedema. The second chapter (Chapter 5) is a collection of empirical studies conducted on distress in this population.





## **Chapter 4. Literature review: Psychological distress in women with breast cancer-related lymphoedema**

Lymphoedema impacts negatively on an individual both physically and psychosocially. Women living with breast cancer-related lymphoedema face symptoms such as swelling, pain, and limited physical mobility (Fu & Rosedale, 2009). These women also face the burden of following a prescribed self-management regimen that includes numerous behaviours to minimise symptoms and slow illness progression, including wearing a compression garment and performing self-lymphatic drainage (massage) (Mayrovitz, 2009). From a psychosocial perspective, lymphoedema may lead to poorer quality of life (Chachaj et al., 2010; Heiney et al., 2007; Mak et al., 2009) and body image disturbance (Burkhardt et al., 2015; Fu et al., 2013; Ridner, Bonner, Deng, & Sinclair, 2012; Ridner, Sinclair, et al., 2012). Thus, living with lymphoedema presents a number of physical, psychological and practical challenges that may contribute to the experience of psychological distress (Chachaj et al., 2010; Fu et al., 2013).

There is no consistent definition of psychological distressed used in the breast cancer-related lymphoedema literature. Most often, the construct of psychological distress is used as an umbrella-term that covers depression and anxiety; however, psychological distress is sometimes used more generally to cover psychological/emotional well-being and mood states. It is common for psychological distress to be operationally defined as a score on a self-reported patient outcome measure, such as the General Health Questionnaire (GHQ-30) (Goldberg & Hillier, 2009), the Centre for Epidemiological Studies Depression scale (CES-D) (Radloff, 1977) or the Depression, Anxiety and Stress Scale (DASS) (Lovibond & Lovibond,

1995). Due to the variation in measures and definitions of distress across studies in the area of breast cancer-related lymphoedema, psychological distress is used as an umbrella term for the purposes of this review and includes any negative emotional state or lack of psychological adjustment.

To date, there has not yet been a review of the research published on psychological distress in women with breast cancer-related lymphoedema. However, previous reviews have investigated the overall psychosocial impact of lymphoedema (Fu et al., 2013; McWayne & Heiney, 2005; Passik & McDonald, 1998; Ridner, 2009) and the impact of lymphoedema on quality of life (Morgan, Franks, & Moffatt, 2005; Taghian, Miller, Jammallo, O'Toole, & Skolny, 2014); these reviews included studies on psychological distress. The majority of reviews suggest that breast cancer-related lymphoedema is associated with psychological distress (Morgan et al., 2005; Passik & McDonald, 1998; Ridner, 2009; Taghian et al., 2014). The exception is a recent systematic review (Fu et al., 2013) that concluded that the results from quantitative studies are inconsistent: Some studies found higher levels of psychological distress amongst women with breast cancer-related lymphoedema in comparison to breast cancer survivors without lymphoedema, whereas other studies found no significant difference between these two groups. Despite inconsistencies in the outcomes of quantitative studies, participants with lymphoedema consistently report negative emotions and distress in qualitative studies (Fu et al., 2013). Together, the published reviews to date highlight that psychological distress is indeed a concern for women diagnosed with breast cancer-related lymphoedema, but it is not yet clear if breast cancer survivors who develop lymphoedema experience higher levels of distress compared to breast cancer survivors who do not develop lymphoedema. Previous

reviews have not specifically addressed this question. Furthermore, no known published review has investigated factors associated with psychological distress.

The purpose of this review is to: (1) determine if previous research has identified higher levels of distress in women living with breast cancer-related lymphoedema in comparison to breast cancer survivors without lymphoedema, and (2) identify factors associated with psychological distress in breast cancer-related lymphoedema.

## **Method**

### **Literature search strategy and inclusion criteria**

A literature search was conducted to identify published research, both qualitative and quantitative, that examined psychological distress and related outcomes in breast cancer patients with lymphoedema. Studies were included in the review if their samples included women diagnosed with breast cancer-related lymphoedema and if they measured, or interviewed participants about, psychological distress. Seven databases were searched (AMED, CINAHL, EMBASE, MEDLINE, PsycINFO, PubMed and Scopus) using combinations of the following search terms: “lymphedema”, “lymphoedema”, “psychological distress”, “depression”, “anxiety” or “stress”.

### **Data extraction and analysis**

Included studies were first separated into two groups: (1) studies that compared levels of psychological distress between breast cancer patients with and without lymphoedema, and (2) studies that analysed factors related to psychological distress in breast cancer patients with lymphoedema. Within each group, studies were further

separated into qualitative, quantitative or mixed method design. All studies were analysed to extract data regarding location, sample characteristics (sample size, age, diagnosis, ethnicity), measures of distress used, and key findings. A meta-analysis was not undertaken due to the heterogeneity of the quantitative studies included and diversity of psychological distress measures used across studies.

### **Quality assessment of included studies**

A validated assessment tool (Harden & Thomas, 2005; Long & Godfrey, 2004) was used to evaluate the quality of included studies. This tool was used in recent systematic reviews on the psychosocial impact of lymphoedema (Fu et al., 2013) and cancer (Osborn, 2007; Wakefield et al., 2010) that, similar to this review, included both quantitative and qualitative studies. The quality assessment tool consists of 10 criteria that apply to both qualitative and quantitative studies and an additional two criteria specific to quantitative studies and two criteria specific to qualitative studies. Thus, each study was evaluated against a total of 12 quality assessment criteria (Table 4.1). Studies were awarded one point for each quality assessment criterion they met, and points were summed for a total quality assessment score (possible range 0 to 12). Studies were then categorised by their total quality assessment score as either high (9-12), moderate (5-8), or low (0-4) quality.

## **Results**

### **Literature search results**

A total of 447 articles were identified and 22 articles remained after removing duplicates and applying the exclusion criteria (non-breast cancer-related lymphoedema, psychological distress not measured, non-English language, or non-peer reviewed

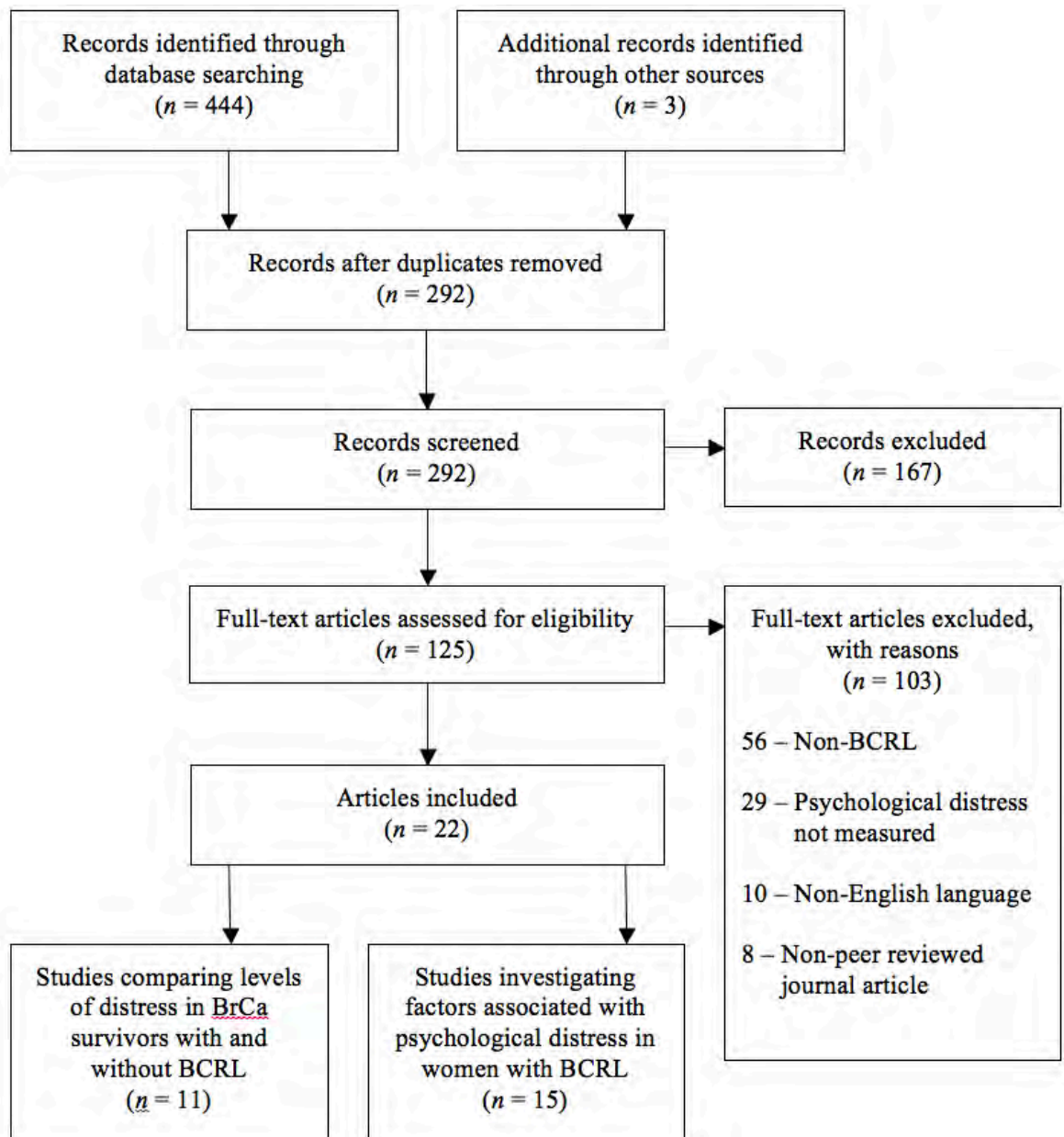
**Table 4.1** Quality assessment tool.

<b>Quality Assessment criteria</b>	<b>Studies that did not meet the criteria</b>
Explicit and sound literature review	Mak et al. (2009)
Clear aims and objectives	
Clear description of setting	Oliveri et al. (2008) Tsuchiya (2014) Vassard et al. (2010)
Clear description of sample	Barlow et al. (2014) Dominick et al. (2014) Tsuchiya (2014)
Appropriate sampling procedure	
Provision of recruitment data	Ridner, Sinclair et al. (2012) Tobin et al. (1993)
Provision of attrition data	
Findings reported for each outcome	Ridner (2005)
Description of validity/reliability of results	Ahmed et al. (2008) Barlow et al. (2014) Chachaj et al. (2010)
Provision of strengths and limitations of the study	
Appropriate statistical analyses (Quantitative)	Passik (1995) Tobin et al. (1993)
Provision of psychometric properties of the measurement instruments (Quantitative)	Chachaj et al. (2010) Kornblith (2003) Ridner, Sinclair et al. (2012) Passik (1995) Pyzsel et al. (2006)
Evidence of critical reflection (Qualitative)	
Sufficient original data (Qualitative)	

journal article; see Figure 4.1). Of the 22 studies, 14 were quantitative, including 13 cross-sectional (Ahmed, Prizment, Lazovich, Schmitz, & Folsom, 2008; Chachaj et al., 2010; Dominick, Natarajan, Pierce, Madanat, & Madlensky, 2014; Khan, Amatya, Pallant, & Rajapaksa, 2012; Kornblith et al., 2003; Mak et al., 2009; Oliveri et al., 2008; Passik, Newman, Brennan, & Tunkel, 1995; Pyszel, Malyszczak, Pyszel, Andrzejak, & Szuba, 2006; Teo, Novy, Chang, Cox, & Fingeret, 2015; Tobin, Lacey, Meyer, & Mortimer, 1993; Tsuchiya, Horn, & Ingham, 2008; Tsuchiya, 2014) and one prospective cohort study (Vassard et al., 2010), and six were qualitative, including one case study (Newman, Brennan, & Passik, 1996), three studies involving interviews (Carter, 1997; Fu & Rosedale, 2009; Heppner et al., 2009), one study involving both interviews and focus groups (Barlow et al., 2014) and one study that used expressive writing to collect data (Ridner, Bonner, et al., 2012). Two studies utilised mixed methods (Ridner, 2005; Ridner, Sinclair, et al., 2012).

### **Characteristics of included studies**

**Participant characteristics.** Sample size varied from 1 (case study) to 133 for the qualitative studies ( $Med = 22$ ), and from 53 to 2431 for the quantitative studies ( $Med = 160$ ). A total of 6564 breast cancer survivors were included across all studies, grouped as either diagnosed with breast cancer-related lymphoedema ( $n = 1990$ ), reporting symptoms of breast cancer-related lymphoedema ( $n = 688$ ) or not diagnosed with lymphoedema ( $n = 3886$ ). The majority of the studies were conducted in the United States (59.1%). All studies except one (Dominick et al., 2014) reported participant age (mean, median and/or range), ranging from 31 to 88. Of the 12 studies that reported ethnicity data (Fu & Rosedale, 2009; Heppner et al., 2009; Kornblith et al., 2003; Mak et al., 2009; Newman et al., 1996; Oliveri et al., 2008; Passik et al., 1995; Ridner, 2005;



**Figure 4.1** Review method flow diagram.

*Note:* BCRL = breast cancer-related lymphoedema, BrCa = breast cancer.

Ridner, Sinclair, et al., 2012; Teo et al., 2015; Tsuchiya et al., 2008; Tsuchiya, 2014) most reported Caucasian-majority samples. Participant characteristics for each study are summarised in Table 4.2 and 4.3.

**Measures.** A variety of measures were used to assess psychological distress, psychological functioning, mental health, emotional well-being and psychological aspects of quality of life. A list of the measures of psychological distress used in the included studies along with a summary of the main purpose and subscales of these measures is displayed in Table 4.4. The measures that have been validated for use in the breast cancer population include the Brief Symptom Inventory (BSI; Galdón et al., 2008), Center for Epidemiologic Studies Depression Scale (CES-D; Hann, Winter, & Jacobsen, 1999), General Health Questionnaire (GHQ-30; Hughson, Cooper, McArdle, & Smith, 1988), Short Form Profile of Mood States (POMS-SF; Baker, Denniston, Zabora, Polland, & Dudley) and Hospital Anxiety and Depression Scale (Bjelland, Dahl, Tangen Haug, & Neckelmann, 2002). None of the measures have been evaluated for use with patients with lymphoedema.

### **Quality of included studies**

The quality assessment of included studies resulted in all studies being awarded a high total quality assessment score (*range* = 10-12 out of a possible 12 points). All of the studies clearly stated their aims and objectives, used an appropriate sampling procedure, provided attrition data when applicable and discussed strengths and limitations. All of the qualitative studies showed evidence of critical reflection and included sufficient original data. Studies that were not awarded a point for a particular criterion are listed in Table 4.1 against the relevant criterion. The most common weaknesses across studies included lacking a clear description of the study setting



**Table 4.2** A summary of the studies that compared levels of psychological distress between breast cancer survivors with and without lymphoedema.

Reference	Aim	Design and location	Sample	Distress measure(s)	Key findings and quality assessment
<b>Quantitative studies</b>					
Tobin et al. (1993)	To evaluate the psychological morbidity associated with arm swelling.	Quantitative Cross-sectional  UK	$N = 100$ ( $n = 50$ BCRL, $n = 50$ non-BCRL)  Age: $M = 56.7$ ( $SE = 1.2$ ) BCRL, $M = 55.9$ ( $SE = 1.06$ ) non-BCRL  Ethnicity: N	Hospital Anxiety and Depression Scale (HADS)	No significant difference between groups for depression and anxiety.  Unpredictable swelling, concerns about appearance, and loss of interest in socialising were related to distress.  Quality assessment score = 10/12
Kornblith et al. (2003)	To describe the long-term	Quantitative Cross-	$N = 153$ (Approximately $n = 59$	Brief Symptom Inventory (BSI)	Lymphoedema that interfered with physical functioning was

Reference	Aim	Design and location	Sample	Distress measure(s)	Key findings and quality assessment
	adaptation of a cohort of BrCa survivors.	sectional  USA	BRCL, <i>n</i> = 94 non-BCRL)  Age: <i>M</i> = 65 ( <i>Range</i> = 41-87)  Ethnicity: 78% White (USA)		significantly associated with greater psychological distress in the bivariate analyses, but not in multivariate analyses.  Quality assessment score = 11/12
Pyszel et al. (2006)	To assess disability, psychological distress and quality of life in Polish BrCa survivors with arm lymphoedema.	Quantitative Cross-sectional  Poland	<i>N</i> = 265 ( <i>n</i> = 84 BCRL, <i>n</i> = 181 non-BCRL)  Age: <i>Med</i> = 57 ( <i>Range</i> = 40-77) BCRL, <i>Med</i> = 57 ( <i>Range</i> = 31-80) non-BCRL  Ethnicity: N	General Health Questionnaire (GHQ-30)	Women with BCRL had higher levels of psychological distress and lower levels of emotional functioning compared to BrCa survivors without BCRL.  Quality assessment score = 11/12

Reference	Aim	Design and location	Sample	Distress measure(s)	Key findings and quality assessment
Ahmed et al. (2008)	To examine the impact of lymphoedema or related arm symptoms on health-related quality of life in BrCa survivors.	Quantitative Cross-sectional USA	$N = 1287$ ( $n = 104$ BCRL, $n = 475$ symptoms of BCRL, $n = 708$ non-BCRL)  Age: <i>Range</i> = 55-69  Ethnicity: N	Medical Outcomes Study Short Form-36 (SF-36)	No significant difference between BCRL and other groups for mental health subscale of the SF-36.  Women with arm symptoms had lower mental health scores in comparison to women without symptoms and women with BCRL.  Quality assessment score = 11/12
Oliveri et al. (2008)	To describe the prevalence and characteristics of lymphoedema-	Quantitative Cross-sectional	$N = 245$ ( $n = 75$ symptoms of BCRL, $n = 170$ non-BCRL)	Center for Epidemiologic Studies – Depression (CES-D) Medical Outcomes Study	No significant difference between participants reporting swelling and those with no swelling on measures of

Reference	Aim	Design and location	Sample	Distress measure(s)	Key findings and quality assessment
	related swelling and document the impact of swelling on perceived physical functioning and mental health.	USA	Age: $M = 63$ ( $SD = 10$ )  Ethnicity: 94% White	Short Form (SF-36)	depression or general mental health.  Nonsignificant trend towards an association between severe swelling and depression and poorer mental health.  Quality assessment score = 11/12
Mak et al. (2009)	To determine the magnitude of arm symptom-associated distress and quality of life in patients suffering from	Quantitative Cross-sectional  Hong Kong, SAR	$N = 202$ ( $n = 101$ BCRL, $n = 101$ non-BCRL)  Age: $M = 51.2$ (8.8)	FACT-B+4	Participants with BCRL had significantly lower scores on FACT-B+4 QoL measure in comparison to BrCa survivors without BCRL, but there was no significant difference

Reference	Aim	Design and location	Sample	Distress measure(s)	Key findings and quality assessment
	lymphoedema after axillary dissection for BrCa.		Ethnicity: 100% Chinese		between groups on the emotional well-being subscale of the same measure.  Quality assessment score = 11/12
Chachaj et al. (2010)	To identify factors associated with worse physical and emotional functioning of BrCa survivors with upper extremity lymphoedema.	Quantitative Cross-sectional Poland	$N = 328$ ( $n = 117$ BCRL, $n = 211$ non-BCRL)  Age: $M = 61.39$ ( $SD = 9.44$ ) BCRL, $M = 59.95$ ( $SD = 10.56$ ) non-BCRL  Ethnicity: N	General Health Questionnaire (GHQ-30)	Participants with BCRL had significantly poorer quality of life and increased psychological distress compared to BrCa survivors without BCRL.  Psychological distress was associated with pain, physical limitations, chemotherapy, and a history of

Reference	Aim	Design and location	Sample	Distress measure(s)	Key findings and quality assessment
					<p>dermatolymphangioadenitis (i.e., an acute inflammation of the skin, lymphatic vessels and nodes in the area of the body affected by lymphoedema).</p> <p>Quality assessment score = 10/12</p>
Vassard et al. (2010)	To investigate the emotional and psychological aspects of living with lymphoedema, including psychological distress, poorer	Quantitative Prospective cohort  Denmark	<p><math>N = 633</math> Baseline (<math>n = 125</math> BCRL, <math>n = 508</math> non-BCRL)</p> <p>Age: <i>Med</i> group = 45-55</p> <p>Ethnicity: N</p>	Profile of Mood States (POMS-SF)	<p>Participants with BCRL had a statistically significant higher risk of scoring higher on the POMS-SF scale in comparison to BrCa survivors without BCRL.</p> <p>Over a 12 month period,</p>

Reference	Aim	Design and location	Sample	Distress measure(s)	Key findings and quality assessment
	quality of life and poorer self-reported health.				women with BCRL scored lower on measures of quality of life.  Results suggest lymphoedema is associated with poorer emotional well-being.  Quality assessment score = 11/12
Khan et al. (2012)	To examine factors impacting long-term functional outcomes and psychological sequelae in survivors of BrCa.	Quantitative Cross-sectional  Australia	$N = 85$ ( $n = 25$ BCRL, $n = 60$ non-BCRL)  Age: <i>Med</i> = 57 ( <i>IQR</i> = 47.4-63.9)  Ethnicity: N	Depression, Anxiety, Stress Scales - 21 (DASS-21)	Participants with BCRL had significantly higher levels of psychological distress compared to BrCa survivors without BCRL.  Pain and upper limb weakness were significantly associated

Reference	Aim	Design and location	Sample	Distress measure(s)	Key findings and quality assessment
					with psychological distress.
					Quality assessment score = 12/12
Dominick et al. (2014)	To examine the impact of self-reported lymphoedema-related distress on psychosocial functioning among BrCa survivors.	Quantitative Cross-sectional USA	$N = 2431$ ( $n = 692$ BCRL, $n = 1739$ non-BCRL)  Age: N  Ethnicity: N	Center for Epidemiologic Studies – Depression (CES-D)  Medical Outcomes Study Short Form (SF-36)	Participants with BCRL were significantly more likely to report poor mental health and depressive symptoms in comparison to BrCa survivors without BCRL.  Number of symptoms significantly associated with lymphoedema-related distress.  Quality assessment score = 11/12



Reference	Aim	Design and location	Sample	Distress measure(s)	Key findings and quality assessment
<b>Mixed methods study</b>					
Ridner (2005)	To compare quality of life and symptoms between BrCa survivors who have developed lymphoedema with those who have not developed lymphoedema.	Mixed methods  Quantitative  Cross-sectional  Qualitative  Open-ended questions  USA	$N = 128$  ( $n = 64$ BCRL, $n = 64$ non-BCRL)  Age: $M = 58$ ( $SD = 10.2$ ) BCRL, $M = 55$ ( $SD = 8.9$ ) non-BCRL  Ethnicity: 90% Caucasian	Centre for Epidemiological Studies of Depression Scale (CESD)  Profile of Mood States-Short Form (POMS-SF)	No significant differences between groups for depression, but women with BCRL scored lower on QoL mood measures indicating higher psychological distress in comparison to BrCa survivors without lymphoedema.  Quality assessment score = 11/12

*Note:* BCRL = diagnosed with breast cancer-related lymphoedema; BrCa = breast cancer; QoL = quality of life; N = not reported.



(Oliveri et al., 2008; Tsuchiya, 2014; Vassard et al., 2010) and sample (Barlow et al., 2014; Dominick et al., 2014; Tsuchiya, 2014), not discussing the validity/reliability of the results (Ahmed et al., 2008; Barlow et al., 2014; Chachaj et al., 2010) and not providing the psychometric properties of study measures (Chachaj et al., 2010; Kornblith et al., 2003; Passik et al., 1995; Pyszel et al., 2006; Ridner, Sinclair, et al., 2012). Quality assessment scores for each individual study are included along with the study characteristics and key findings in Table 4.2 (studies comparing levels of psychological distress in breast cancer survivors with and without lymphoedema) and Table 4.3 (studies investigating factors associated with distress in women with breast cancer-related lymphoedema).

### **Psychological distress associated with breast cancer-related lymphoedema**

Of the included studies, 11 compared levels of distress in breast cancer survivors with and without lymphoedema (Ahmed et al., 2008; Chachaj et al., 2010; Dominick et al., 2014; Khan et al., 2012; Kornblith et al., 2003; Mak et al., 2009; Oliveri et al., 2008; Pyszel et al., 2006; Ridner, 2005; Tobin et al., 1993; Vassard et al., 2010). A summary of the data extraction and analysis results for each study that compared levels of distress between breast cancer survivors with and without lymphoedema is provided in Table 4.2. Five of the studies found significantly higher levels of psychological distress in breast cancer survivors with lymphoedema in comparison to breast cancer survivors without lymphoedema (Chachaj et al., 2010; Dominick et al., 2014; Khan et al., 2012; Pyszel et al., 2006; Vassard et al., 2010). Related findings include significantly poorer quality of life (Ridner, 2005) and adjustment to illness (Vassard et al., 2010) and greater psychiatric morbidity (i.e., anxiety and depression according to a formal diagnostic interview) and mood disturbance (Tobin et al., 1993) amongst breast cancer survivors

with lymphoedema in comparison to breast cancer survivors without lymphoedema.

Conversely, a slight majority of studies found no significant difference for psychological distress between the two groups (Ahmed et al., 2008; Kornblith et al., 2003; Mak et al., 2009; Oliveri et al., 2008; Ridner, 2005; Tobin et al., 1993).

### **Factors associated with psychological distress amongst women with breast cancer-related lymphoedema.**

Of the included studies, 14 investigated factors associated with psychological distress in women with breast cancer-related lymphoedema (Barlow et al., 2014; Carter, 1997; Chachaj et al., 2010; Dominick et al., 2014; Fu & Rosedale, 2009; Heppner et al., 2009; Khan et al., 2012; Newman et al., 1996; Passik et al., 1995; Ridner, Bonner, et al., 2012; Ridner, Sinclair, et al., 2012; Teo et al., 2015; Tsuchiya et al., 2008; Tsuchiya, 2014). It is important to note that none of the included studies were longitudinal; therefore, it is not possible to infer whether or not identified factors actually cause or contribute to the development of psychological distress. A summary of the data extraction and analysis results for each study investigating factors associated with distress in women with breast cancer-related lymphoedema is provided in Table 4.3. Only three of the studies included in this review (Chachaj et al., 2010; Passik et al., 1995; Teo et al., 2015) specifically aimed to identify potential factors (e.g., medical and psychosocial) associated with psychological distress. However, a number of quantitative studies conducted secondary analyses (Dominick et al., 2014; Khan et al., 2012; Tsuchiya et al., 2008; Tsuchiya, 2014) to look for factors significantly associated with distress. In addition, several qualitative studies (Carter, 1997; Fu & Rosedale, 2009; Heppner et al., 2009; Newman et al., 1996; Ridner, Bonner, et al., 2012; Ridner, Sinclair, et al., 2012) have identified sources of distress reported by participants.

**Table 4.3** A summary of the studies that discussed factors associated with psychological distress.

Reference	Aim	Design and location	Sample	Distress measure(s)	Key findings and quality assessment
<b>Quantitative studies</b>					
Passik et al. (1995)	To determine possible associations among upper-limb lymphoedema and psychosocial problems.	Quantitative Cross-sectional  USA	$N = 69$ BCRL  Age: $M = 57.42$ ( $SD = 12.5$ )  Ethnicity: 82.4% Caucasian	Brief Symptom Inventory (BSI)	Psychological distress was associated with pain, insufficient social support, an avoidant coping style and the dominant arm affected.  Quality assessment score = 10/12
Tsuchiya et al. (2008)	To assess the relationships between lymphoedema symptom-related	Quantitative Cross-sectional  Japan	$N = 138$ (Symptoms of BCRL)  Age: $M = 56.1$ ( $SD = 8.3$ )	World Health Organization (WHO) QoL-BREF (Japanese version)	Participants who reported pain and physical discomfort in daily activities had significantly worse psychological QoL scores.

Reference	Aim	Design and location	Sample	Distress measure(s)	Key findings and quality assessment
	variables and QoL among Japanese women with BrCa who had undergone surgery.		Ethnicity: 100% Japanese		Quality assessment score = 12/12
Chachaj et al. (2010)	To identify factors associated with worse physical and emotional functioning of BrCa survivors with upper extremity lymphoedema.	Quantitative Cross-sectional Poland	<i>N</i> = 328 ( <i>n</i> = 117 BCRL, <i>n</i> = 211 non-BCRL)  Age: <i>M</i> = 61.39 ( <i>SD</i> = 9.44) BCRL, <i>M</i> = 59.95 ( <i>SD</i> = 10.56) non-BCRL  Ethnicity: N	General Health Questionnaire (GHQ-30)	Psychological distress was associated with pain, physical limitations, chemotherapy, and a history of dermatolymphangioadenitis.  Participants with BCRL had significantly poorer quality of life and increased psychological distress compared to participants

Reference	Aim	Design and location	Sample	Distress measure(s)	Key findings and quality assessment
					without BCRL.
					Quality assessment score = 10/12
Khan et al. (2012)	To examine factors impacting long-term functional outcomes and psychological sequelae in survivors of BrCa.	Quantitative Cross-sectional  Australia	<i>N</i> = 85  ( <i>n</i> = 25 BCRL, <i>n</i> = 60 non-BCRL)  Age: <i>Med</i> = 57 ( <i>IQR</i> = 47.4-63.9)  Ethnicity: N	Depression, Anxiety, Stress Scales - 21 (DASS-21)	Participants with BCRL had significantly higher levels of psychological distress.  Pain and upper limb weakness were significantly associated with psychological distress.  Quality assessment score = 12/12
Dominick et al. (2014)	To examine the impact of self-reported	Quantitative Cross-sectional	<i>N</i> = 2431  ( <i>n</i> = 692 BCRL, <i>n</i> = 1739 non-BCRL)	Center for Epidemiologic Studies – Depression (CES-D)	Participants with BCRL were significantly more likely to report poor mental health and

Reference	Aim	Design and location	Sample	Distress measure(s)	Key findings and quality assessment
	lymphoedema-related distress on psychosocial functioning among BrCa survivors.	USA	Age: N  Ethnicity: N	Medical Outcomes Study Short Form (SF-36)	depressive symptoms in comparison to BrCa survivors without BCRL.  Number of symptoms significantly associated with lymphoedema-related distress.  Quality assessment score = 11/12
Tsuchiya (2014)	To examine the effects of perceptions of information received about upper-limb	Quantitative Cross-sectional  Japan	$N = 166$ BCRL  Age: $M = 56.32$ ( $SD = 7.99$ )  Ethnicity: 100%	WHO QoL-BREF Japanese version	Poor psychological health was associated with perceived insufficient information provision, negative perceptions of lymphoedema symptoms, and symptom



Reference	Aim	Design and location	Sample	Distress measure(s)	Key findings and quality assessment
	morbidity and perceptions of upper-limb symptoms on quality of life among Japanese BrCa survivors.		Japanese		disclosure.  Quality assessment score = 10/12
Teo et al. (2015)	To examine body image dissatisfaction as a potential mediator between pain, body integrity beliefs and depression.	Quantitative Cross-sectional  USA	<i>N</i> = 54 BCRL  Age: <i>M</i> = 57 ( <i>SD</i> = 9)  Ethnicity: 93% not Hispanic or latino	PROMIS Depression Short Form v1.0	Pain and body integrity beliefs were associated with depressive symptoms.  Body image dissatisfaction mediated the relationship between pain and body integrity beliefs and depressive symptoms.  Quality assessment score =

Reference	Aim	Design and location	Sample	Distress measure(s)	Key findings and quality assessment
					12/12
<b>Qualitative studies</b>					
Newman et al. (1996)	To present a case study that illustrates the complexity of lymphoedema treatment in the context of ongoing pain and psychological distress.	Qualitative Case study  USA	<i>N</i> = 1 BCRL  Age: 55  Ethnicity: Hispanic		Patient experienced psychological distress (depression) not aided by psychopharmacological treatment.  Treatment for pain led to improvements in psychological distress.  Quality assessment score = 12/12
Carter (1997)	To explore women's experiences of	Qualitative Interviews	<i>N</i> = 10 BCRL  Age: <i>Range</i> = 36-75		Participants reported that difficulties with work, sexuality and social

Reference	Aim	Design and location	Sample	Distress measure(s)	Key findings and quality assessment
	lymphoedema.	USA	Ethnicity: N		<p>relationships contributed to psychological distress.</p> <p>Distress also reported in response to health professionals with limited knowledge about lymphoedema, receiving inconsistent information regarding treatment and having limited access to treatment.</p> <p>Quality assessment score = 12/12</p>
Fu and Rosedale (2009)	To explore and describe BrCa survivors'	Qualitative Phenomenological Interviews	<p><math>N = 34</math> BCRL</p> <p>Age: <math>M = 55</math> (Range =</p>		Patients reported that persistent symptoms, and lymphoedema's negative

Reference	Aim	Design and location	Sample	Distress measure(s)	Key findings and quality assessment
	lymphoedema-related symptom experiences.	USA	35-86)  Ethnicity: 38.2% Chinese American, 32.4% African American, 29.4% Caucasian		<p>impact on activities of daily living, childcare, employment and appearance were sources of distress.</p> <p>Additional reported sources of distress include unexpected situations, lack of knowledge about lymphoedema (on the part of both patients and health professionals) and changes to self-identity.</p> <p>Quality assessment score = 12/12</p>
Heppner et al. (2009)	To promote greater understanding	Qualitative Interviews	<p><i>N</i> = 10 BCRL</p> <p>Age: <i>M</i> = 58.6 (<i>Range</i></p>		Participants reported that the negative impact of lymphoedema on appearance

Reference	Aim	Design and location	Sample	Distress measure(s)	Key findings and quality assessment
	among counsellors and other helping professionals regarding the stressors associated with lymphoedema, how women cope with the stressors, and the role of social support.	USA	= 47-88)  Ethnicity: 100% Caucasian		and sexuality as well as the distress experienced by partners and children were sources of distress.  Quality assessment score = 12/12
Ridner, Bonner, et al. (2012)	To explore perceptions and feelings related to lymphoedema	Qualitative Expressive writing  USA	<i>N</i> = 39 BCRL  Age: <i>M</i> = 55.31 ( <i>SD</i> = 10.14)		Body image disturbance, physical limitations, negative impact on relationships, loss of control, and uncertainty contribute to distress.

Reference	Aim	Design and location	Sample	Distress measure(s)	Key findings and quality assessment
	in BrCa survivors.		Ethnicity: 79.5% Caucasian, 17.9% African American, 2.6% other		Social support and spirituality help women cope with lymphoedema.  Quality assessment score = 12/12
Barlow et al. (2014)	To explore women's views of their care and treatment following a diagnosis with lymphoedema secondary to cancer.	Qualitative Interviews, focus groups and open-ended questions  UK	<i>N</i> = 133 BCRL ( <i>n</i> = 14 interviews, <i>n</i> = 15 focus groups, <i>n</i> = 104 open-ended questions)  Ethnicity: N		A lack of support from health professionals reported as a source of distress.  Overall, found lack of support from medical community for women with BCRL to help prevent or resolve their distress.

Reference	Aim	Design and location	Sample	Distress measure(s)	Key findings and quality assessment
					Quality assessment score = 10/12
<b>Mixed methods study</b>					
Ridner, Sinclair, et al. (2012)	To determine whether lymphoedema is a disabling condition by collecting symptom data and self-generated narratives.	Mixed method Quantitative Cross-sectional Qualitative Expressive writing USA	<i>N</i> = 53 BCRL Ethnicity: 89%		Distress was associated with decreased social activity, loss of intimacy in relationships, body image challenges, lack of self-confidence and physical challenges.  Quality assessment score = 10/12

*Note:* BrCa = breast cancer; QoL = quality of life; BCRL = diagnosed with breast cancer-related lymphoedema; N = not reported.





First, the seven quantitative studies (Chachaj et al., 2010; Chua, DeSantis, Teo, & Fingeret, 2015; Dominick et al., 2014; Khan et al., 2012; Passik et al., 1995; Tsuchiya et al., 2008; Tsuchiya, 2014) identified both medical and psychosocial factors associated with distress. Regarding medical factors, the total number of lymphoedema symptoms women experience seem to be significantly associated with distress (Dominick et al., 2014), as well as negative perceptions of these symptoms (Tsuchiya, 2014). More specifically, pain is most commonly found to be significantly associated with increased levels of distress (Chachaj et al., 2010; Khan et al., 2012; Passik et al., 1995; Teo et al., 2015) and poorer psychological quality of life (Tsuchiya et al., 2008). Similarly, the physical limitations caused by lymphoedema are also associated with distress (Chachaj et al., 2010; Khan et al., 2012). Other medical factors found to be associated with distress include having the dominant arm affected (Passik et al., 1995), having undergone chemotherapy for breast cancer (Chachaj et al., 2010) and having experienced dermatolymphangioadenitis (i.e., an acute inflammation of the skin, lymphatic vessels and nodes in the area of the body affected by lymphoedema) (Chachaj et al., 2010). A number of psychosocial factors were found to be significantly associated with distress, including a lack of social support and an avoidant coping style (Passik et al., 1995), inadequate information provision (Tsuchiya, 2014), and body integrity beliefs (i.e., an individual's value of an intact body for self-worth) (Teo et al., 2015). Furthermore, the results of one study suggests that body image disturbance may mediate the relationship between body integrity beliefs and depression (Teo et al., 2015). In this study, greater body integrity beliefs were associated with greater body image disturbance which, in turn, was associated with symptoms of depression. Note, however, that the results of cross-sectional studies may not be not an accurate reflection of longitudinal mediation (Cole & Maxwell, 2003; Maxwell & Cole, 2007).



**Table 4.4** Measures of psychological distress used in previous research on breast cancer-related lymphoedema.

<b>Measure</b>	<b>Main purpose</b>	<b>Relevant studies</b>
Brief Symptom Inventory (BSI) (Derogatis & Melisaratos, 1983)	To detect psychological problems, including depression and anxiety, in both clinical and general populations. <i>Subscales:</i> Somatization, obsessive-compulsive, interpersonal sensitivity, depression, anxiety, hostility, phobic anxiety, paranoid ideation and psychoticism.	Kornblith et al. (2003) Passik et al. (1995)
Center for Epidemiologic Studies Depression Scale (CES-D) (Radloff, 1977)	To assess symptoms of depression in the general population. Subscales: Somatic, depressed affect, positive affect and interpersonal.	Dominick et al. (2014) Oliveri et al. (2008) Ridner (2005)
Depression, Anxiety and Stress Scales (DASS-21) (Lovibond & Lovibond, 1995)	To measure depression, anxiety and stress in both clinical and general populations. <i>Subscales:</i> Depression, anxiety and stress.	Khan et al. (2012)
Functional Assessment of Cancer Therapy – Breast Cancer (FACT-B) (Brady et al., 1997)	To assess physical, social, emotional and functional domains of quality of life in patients with breast cancer. <i>Subscales:</i> Physical well-being, functional well-being and emotional	Mak et al. (2009)

Measure	Main purpose	Relevant studies
	well-being.	
General Health Questionnaire (GHQ-30) (Goldberg & Hillier, 2009)	To screen for psychological distress. <i>Subscales:</i> Anxiety, depression, somatic symptoms and social dysfunction.	Chachaj et al. (2010) Pyszel et al. (2006)
Hospital Anxiety and Depression Scale (HADS) (Zigmond & Snaith, 1983)	To measure psychological distress. <i>Subscales:</i> Anxiety and depression.	Tobin et al. (1993)
Profile of Mood States (POMS-SF) (Curran, Andrykowski, & Studts, 1995)	To measure mood states. <i>Subscales:</i> Fatigue-Inertia, Vigor-Activity, Tension-Anxiety, Depression-Dejection, Anger-Hostility and Confusion-Bewilderment.	Ridner (2005) Vassard et al. (2010)
PROMIS Depression Short Form v1.0 (Pilkonis et al., 2011)	To measure depressive symptoms.	Teo et al. (2015)
Medical Outcomes Study Short Form Health Survey (SF-36)	To measure overall physical and mental health in both general and clinical populations.	Ahmed et al. (2008) Dominick et al. (2014)

Measure	Main purpose	Relevant studies
(McHorney et al., 1993)	<i>Subscales:</i> Physical functioning, role-physical, bodily pain, general health, vitality, social functioning, role-emotional and mental health.	Oliveri et al. (2008)
World Health Organization Quality of Life (WHOQOL-BREF) (WHOQoL Group, 1998)	To assess quality of life in a variety of populations. <i>Subscales:</i> Physical health, psychological health, social relationships and environment.	Tsuchiya et al. (2008) Tsuchiya (2014)



Patients' reports of sources of distress found in qualitative studies are consistent with quantitative findings. Lymphoedema symptoms (Fu & Rosedale, 2009), including pain (Newman et al., 1996) and physical limitations (Ridner, Bonner, et al., 2012; Ridner, Sinclair, et al., 2012) emerge as major themes associated with distress. Another medical factor associated with increased levels of distress highlighted in one study is limited access to treatment (Carter, 1997). Lymphoedema's negative impact on activities of daily living and associated distress is a common theme that emerged (Fu & Rosedale, 2009), including employment challenges (Carter, 1997; Fu & Rosedale, 2009) and child care (Fu & Rosedale, 2009). Difficulties with social relationships in general was reported as a source of distress in three studies (Carter, 1997; Ridner, Bonner, et al., 2012; Ridner, Sinclair, et al., 2012), and in another study this included the distress of significant others and children (Heppner et al., 2009). The difficulties that arise with intimate and romantic relationships may be in part due to body image disturbance (Fu & Rosedale, 2009; Heppner et al., 2009; Ridner, Bonner, et al., 2012; Ridner, Sinclair, et al., 2012), changes to women's self-identity (Fu & Rosedale, 2009) and negative impact on sexuality (Carter, 1997; Heppner et al., 2009; Ridner, Sinclair, et al., 2012) that were also reported as sources of distress. Information and knowledge also came up frequently in interviews, with women reporting that limited knowledge on behalf of both themselves (Carter, 1997; Fu & Rosedale, 2009) and health professionals (Carter, 1997; Fu & Rosedale, 2009) contributed to distress. Similarly, one study found that a lack of support from health professionals was a source of distress for patients (Barlow et al., 2014). Finally, a sense of lacking control (Ridner et al., 2012) and unexpected situations (Fu & Rosedale, 2009) were also reported as sources of distress. Only one study discussed factors that may help protect against, or resolve, psychological distress in women with breast cancer-related lymphoedema (Ridner,

Bonner, et al., 2012): Social support and spirituality emerged as major themes that helped women cope with their lymphoedema.

## **Discussion**

### **Psychological distress associated with breast cancer-related lymphoedema**

It is not clear from the results of the studies reviewed if breast cancer survivors that develop lymphoedema subsequently experience significantly higher levels of psychological distress in comparison to breast cancer survivors that do not develop lymphoedema. For the studies that did find significant differences, breast cancer survivors with lymphoedema had higher levels of psychological distress in comparison to breast cancer survivors without lymphoedema (Chachaj et al., 2010; Dominick et al., 2014; Khan et al., 2012; Pyszel et al., 2006). These differences were hypothesised to be attributed to the desire to return to “normal” life after breast cancer treatment being disrupted by the unexpected development of lymphoedema (Pyszel et al., 2006), to lymphoedema being an unwanted reminder of breast cancer that brings up negative emotions and memories (Pyszel et al., 2006), to the pain, symptoms (e.g., fatigue) and reduced physical functioning associated with lymphoedema that may interfere with activities of daily living (Chachaj et al., 2010; Dominick et al., 2014; Pyszel et al., 2006), to the financial burden of lymphoedema (i.e., from either a reduced ability to work and/or cost of treatments such as physiotherapy, massage therapy and compression garments)(Pyszel et al., 2006), and/or to the body image disturbance caused by lymphoedema (Chachaj et al., 2010). However, a slight majority of the studies found no significant differences between the two groups on measures of psychological distress (Ahmed et al., 2008; Kornblith et al., 2003; Mak et al., 2009; Oliveri et al., 2008; Tobin et al., 1993).



There are a number of key differences between these studies that, along with their various limitations, might explain the lack of consistent findings. First, almost every study reviewed used a different measure of psychological distress. A total of 10 different measures were used with little overlap between studies (see Table 4.4). Two studies (Chachaj et al., 2010; Pyszel et al., 2006) used the General Health Questionnaire (GHQ-30) (Goldberg & Hillier, 2009) with similar results, both finding significantly higher levels of distress in women with lymphoedema. However, findings differed between the four studies (Ahmed et al., 2008; Dominick et al., 2014; Oliveri, Day, Alfano, Herndon, et al., 2008; Ridner, 2005) that used the Centre for Epidemiological Studies Depression Scale (CES-D) (Radloff, 1977) and/or the Medical Outcomes Study Short Form Health Survey (SF-36) (McHorney, Ware, & Raczek, 1993). For example, despite each study including both of these measures, Dominick et al. (2014) found that women with lymphoedema-related distress had significantly more symptoms of depression and poorer mental health compared to women without lymphoedema, while Oliveri et al. (2008) found no significant differences between groups. A lack of consistency in measures of psychological distress makes comparisons between studies difficult. Furthermore, none of the studies used a measure that has either been developed specifically for lymphoedema or validated in this population. Second, the samples varied widely in terms of the medical characteristics (e.g., time since breast cancer treatment, time since lymphoedema diagnosis). This heterogeneity of samples found across included studies makes it problematic to determine to what extent distress may reflect participants' recent experience with a diagnosis or treatment.

The studies that compared women with and without breast cancer-related lymphoedema share key limitations that may also explain the inconsistent findings. First, none of the studies included a discussion of relevant theory used as a framework

for the research (Alderson, 1998; Buchanan, 1994). Second, not all studies investigated psychological distress as part of their primary aim, but instead were focused on quality of life (Ahmed et al., 2008; Mak et al., 2009; Ridner, 2005) or physical functioning (Khan et al., 2012). Finally, aside from one prospective study (Vassard et al., 2010), all studies comparing levels of psychological distress between groups were cross-sectional.

In summary, based on the research reviewed it is not possible to draw a conclusion regarding whether or not psychological distress is associated with breast cancer-related lymphoedema when comparing breast cancer survivors with and without the illness. Inconsistent findings across studies are likely due to considerable differences in measures of psychological distress and related constructs as well as the heterogeneity across study samples. Future research could address these inconsistencies using a prospective design to determine if developing lymphoedema post-breast cancer significantly increases survivors' levels of distress.

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

Considering the available evidence discussed above, it seems that the symptoms of lymphoedema are both directly and indirectly a major source of distress for women living with breast cancer-related lymphoedema. Symptoms such as pain and discomfort in the area of the body affected by lymphoedema may be directly associated with distress. This is consistent with findings from the broader literature that pain from a variety of causes (e.g., chronic disease, arthritis, injury) is commonly associated with psychological distress (Bair, Robinson, Katon, & Kroenke, 2003). It is also important to note that patients with both depression and pain experience worse outcomes in comparison with patients who experience either depression or pain alone (Bair et al.,

2003). For this reason, pain management should be a priority for patients with breast cancer-related lymphoedema, and patients reporting pain should be screened for psychological distress.

Symptoms of lymphoedema may also be indirectly associated with psychological distress. For example, women experiencing severe swelling and/or physical limitations from their lymphoedema may be distressed due to the interference with activities of daily living, including fulfilling their various roles and responsibilities at home and work. Another way that symptoms may indirectly lead to psychological distress is through the impact on body image. Lymphoedema can cause significant bodily appearance changes due to extensive and visibly noticeable swelling in the chest and/or arm which also affects a woman's choice of clothing (e.g., being unable to wear slim fitting clothes) (Fu et al., 2013; Rhoten, Radina, Adair, Sinclair, & Ridner, 2015). It is likely that body image disturbance resulting from lymphoedema will be associated with increased psychological distress, as body image disturbance generally has been associated with psychological distress in breast cancer survivors (Schover et al., 1995), especially amongst younger women (Avis, Crawford, & Manuel, 2004; Fobair et al., 2006; Przewdziecki et al., 2013). Evidence from qualitative research supports this view (Fu & Rosedale, 2009; Heppner et al., 2009; Ridner, Bonner, et al., 2012), as does one study that found that body image disturbance mediated the relationships between pain and body integrity beliefs, and pain and depression, in women with breast cancer-related lymphoedema (Teo et al., 2015). Future research is needed to investigate quantitatively the relationship between symptoms, body image disturbance and psychological distress in women with breast cancer-related lymphedema.

In addition to the symptoms of lymphoedema, the other major recurring theme in the literature is both patient and health professional knowledge about lymphoedema.

This is consistent with the broader oncology literature in which lower anxiety and depression is associated with information provision (Davison, Goldenberg, Gleave, & Degner, 2003), fulfilled information needs and less information barriers (Husson, Mols, & van de Poll-Franse, 2011). Thus, previous research supports that information provision and increasing patient knowledge are important for lowering distress, but it may also be worthwhile to investigate health professionals' knowledge of lymphoedema and whether or not this can be improved. If health professionals are more knowledgeable about the development, treatment and self-management of lymphoedema, individuals with lymphoedema may not feel marginalised by health professionals, an area of concern raised in qualitative research (Barlow et al., 2014; Fu et al., 2013; Ridner, Bonner, et al., 2012). In this way, educating health professionals may remove a contributing factor to distress amongst women affected by breast cancer-related lymphoedema.

### **Limitations of previous research**

Although all of the studies included in this review were awarded high scores for overall quality, several common limitations apply across the majority of studies included in this review. Some of these limitations are common in research generally, such as relying on self-reported and/or retrospective data, a lack of random sampling and limited ethnic diversity within samples. However, this section describes three key limitations that are critical to address in future research on breast cancer-related lymphoedema. There is great room for improvement in study design and methodology, and future research should ensure that studies are based in a sound theoretical framework.

**Limited types of study design.** Previous research on the topic of psychological distress in women with breast cancer-related lymphoedema is primarily qualitative or cross-sectional (i.e., only one study utilised a prospective cohort design; Vassard et al., 2010). So far we have accumulated a large amount of rich, qualitative data on women's experiences of lymphoedema and reported sources of distress and this, combined with findings from quantitative studies, provide support for the development of prospective, longitudinal studies. Furthermore, as previous reviews of the literature on breast cancer-related lymphoedema have noted, few studies have the primary aim of investigating the impact of lymphoedema from a psychosocial perspective (Fu et al., 2013; Passik et al., 1995). In fact, almost a third of the studies included in this review analysed a subset of data from larger studies examining a variety of topics, including women's health (Ahmed et al., 2008), breast cancer treatment (Dominick et al., 2014; Kornblith et al., 2003), screening for psychological distress (Barlow et al., 2014), lymphoedema management (Fu & Rosedale, 2009) and rehabilitation from cancer (Vassard et al., 2010). Thus, prospective, longitudinal studies that specifically aim to identify factors that predict psychological distress are needed in order to identify women who may be at risk of poor psychological outcomes as a result of developing lymphoedema.

**Heterogeneity of samples.** The studies conducted on psychological distress in women with breast cancer-related lymphoedema thus far are difficult to compare due to the heterogeneity within and between samples. Only eight of the included studies had specific selection criteria in terms of breast cancer history and/or lymphoedema (e.g., inclusion criteria of early versus late stage breast cancer) (Carter, 1997; Dominick et al., 2014; Fu & Rosedale, 2009; Kornblith et al., 2003; Mak et al., 2009; Passik et al., 1995; Ridner, 2005; Vassard et al., 2010), and so it is not surprising that the other studies varied widely in terms of sample characteristics. This likely reflects the feasibility of

participant recruitment – specific selection criteria may have been too limiting for an adequate sample size to be obtained for at least some of the studies included in this review.

It is challenging to compare distress scores between samples of women with mild versus severe lymphoedema, or who have only completed breast cancer treatment within the past year versus three or more years. It is even more problematic to determine how results may relate to medical history characteristics when these details are not provided. Only a minority of studies provided information about the time since breast cancer diagnosis (Ahmed et al., 2008; Carter, 1997; Fu & Rosedale, 2009; Khan et al., 2012; Oliveri et al., 2008; Passik et al., 1995; Ridner, Bonner, et al., 2012; Ridner, 2005; Ridner, Sinclair, et al., 2012), breast cancer stage (Ahmed et al., 2008; Khan et al., 2012; Mak et al., 2009; Ridner, Bonner, et al., 2012; Ridner, 2005; Ridner, Sinclair, et al., 2012; Tsuchiya et al., 2008; Tsuchiya, 2014; Vassard et al., 2010), time since breast cancer treatment (Chachaj et al., 2010; Kornblith et al., 2003; Mak et al., 2009; Newman et al., 1996; Tsuchiya et al., 2008; Vassard et al., 2010), time since lymphoedema diagnosis (Carter, 1997; Chachaj et al., 2010; Fu & Rosedale, 2009; Heppner et al., 2009; Newman et al., 1996; Oliveri et al., 2008; Ridner, Bonner, et al., 2012; Ridner, 2005; Ridner, Sinclair, et al., 2012; Tobin et al., 1993), or some measure of lymphoedema severity (e.g., stage or symptoms; Chachaj et al., 2010; Dominick et al., 2014; Fu & Rosedale, 2009; Khan et al., 2012; Oliveri et al., 2008; Passik et al., 1995; Ridner, Bonner, et al., 2012; Ridner, 2005; Tobin et al., 1993; Tsuchiya et al., 2008; Tsuchiya, 2014). Furthermore, two studies provided little to no participant medical history information for either breast cancer or lymphoedema (Pyszel et al., 2006; Teo et al., 2015). Future studies should ensure that details are provided about the

sample's medical characteristics to allow for more informed and meaningful comparisons to be made across studies.

**Inconsistent measures.** A variety of general and specific measures were used across studies to assess psychological distress and this limits the ability to compare and synthesise findings across studies included in this review. Findings from studies using quality of life measures with subscales assessing emotional well-being and mental health (Ahmed et al., 2008; Dominick et al., 2014; Mak et al., 2009; Oliveri et al., 2008; Tsuchiya et al., 2008; Tsuchiya, 2014) should be interpreted with caution, because the quality of life measure may not be as sensitive as a measure developed specifically to detect depression, anxiety or stress. That said, the differences in measures in part likely reflect the specific aims of each individual study. Many studies did not specifically aim to measure psychological distress (Ahmed et al., 2008; Kornblith et al., 2003; Ridner, 2005; Tsuchiya et al., 2008; Tsuchiya, 2014); thus, it is not surprising that more general measures of emotional well-being and quality of life were used. Other studies used more specific measures of psychological distress (e.g., HADS; Tobin et al., 1993); however, few studies overlapped by using the same measure and this makes comparisons across studies difficult.

All measures of psychological distress used by the included studies contained items assessing depression, and most of these measures also contained items assessing anxiety. Future research in the lymphoedema context should aim to use a specific measure with good psychometric properties that includes items assessing depression and anxiety, such as the DASS-21 (Crawford, Cayley, Lovibond, Wilson, & Hartley, 2011; Lovibond & Lovibond, 1995) or BSI (Derogatis & Melisaratos, 1983), both of which have clinical norms available for the Australian population. Ideally, future research should also evaluate the use of these measures in the lymphoedema population.

**Lack of theory.** The final major limitation of the literature on psychological distress and breast cancer-related lymphoedema is the lack of theory-based research (Alderson, 1998; Buchanan, 1994). Only two studies applied theory to inform their research design and methodology. Kornblith et al. (2003) applied a “Vulnerability Model” as a framework for understanding women’s psychosocial adaptation to cancer. The researchers used this model to choose a number of factors hypothesised to mediate between the impact of cancer on women’s physical functioning and adjustment outcomes, including social and economic stressors. However, the premises of this theory were not explained in detail and there was no reference to other articles explaining this model. The author of this review could not find information on the vulnerability model when searching research databases. Thus, further investigation is needed to determine if the Vulnerability Model is a suitable framework for understanding psychological distress in breast cancer-related lymphoedema.

The other study (Khan et al., 2012) used the World Health Organization’s International Classification of Functioning, Disability and Health (ICF) as a conceptual framework for measuring the impact of lymphoedema on health and disability. The ICF was developed as a classification system for health and health-related domains of functioning, including functioning and disability (i.e., body functions and structures) and contextual factors (i.e., environmental and personal) (Ustün, Chatterji, Bickenbach, Kostanjsek, & Schneider, 2003). The ICF seems appropriate for the aims of Khan et al.’s study in regards to assessing physical functioning of women with breast cancer-related lymphoedema, however, it is not adequate for assessing the psychosocial impact of the illness.

Where do we go from here? One promising avenue for future research is to investigate the usefulness of the Common Sense Model (CSM) of illness self-regulation



(Diefenbach & Leventhal, 1996) as a theoretical framework for understanding psychological distress in breast cancer-related lymphoedema. The CSM proposes that an individual's response to illness, such as developing lymphoedema, is a function of both cognitive and affective representations of illness-related information. When presented with a health threat, individuals form beliefs and perceptions about the cause, timeline, controllability and consequences of the illness. Individuals also have an emotional response to health threats, such as anger and distress, which are processed in parallel to cognitive beliefs. In turn, these cognitive and emotional representations influence the individual's chosen coping responses and behaviours. The self-regulation aspect of this model consists of the individual's ongoing appraisal of the outcomes of chosen behaviours and coping. Thus, the CSM predicts that illness representations are associated with physical and emotional patient outcomes (Leventhal, Leventhal, & Contrada, 1998). For example, if a patient's beliefs about lymphoedema are violated, he or she may experience psychological distress (Leventhal et al., 1998). This is supported by the finding that unexpected outcomes, such as more severe symptoms and a greater negative impact on activities of daily living than anticipated, were a source of distress for women living with lymphoedema (Fu & Rosedale, 2009).

The CSM has been operationalised by the Illness Perceptions Questionnaire (IPQ) (Weinman, Petrie, Moss-Morris, & Horne, 1996) (assessing beliefs about illness identity, timeline, consequences and cure/control) and the Revised Illness Perceptions Questionnaire (IPQ-R) (Moss-Morris et al., 2002) (updated to assess additional dimensions including beliefs about illness coherence and consequences as well as emotional representations of illness). Illness representations have not yet been measured in women with breast cancer-related lymphoedema, however, we can hypothesise that understanding women's beliefs about lymphoedema, their emotional responses to their

illness, and their self-regulatory processes will also help us gain a greater understanding of what may underlie psychological distress. In support of this, illness representations and psychological distress in individuals living with diabetes has found that illness representations (e.g., beliefs about the consequences of diabetes) accounted for approximately 15% of the variance in diabetes-related distress. In summary, the CSM is a promising framework for future research on understanding psychological distress and breast cancer-related lymphoedema. Furthermore, studies using this framework have validated measures (i.e., the IPQ and IPQ-R) available for operationalising illness representations.

### **Directions for future research**

Future research can help resolve the limitations of the literature on psychological distress and breast cancer-related lymphoedema raised above. Prospective studies can investigate the factors previously found to be associated with psychological distress to determine if they predict levels of psychological distress over time. In addition, future research can be strengthened by being theory-based (Alderson, 1998; Buchanan, 1994). Finally, studies with sound research design and methodology may also resolve the conflicting findings regarding whether or not the development of lymphoedema is associated with increased levels of distress amongst breast cancer survivors.

Another gap that needs to be addressed in the literature on distress in women with breast-cancer related lymphoedema is potentially viable prevention and intervention strategies. One possibility is the use of Proprioceptive Neuromuscular Facilitation (PNF) exercises (Ha & Choi, 2014). The use of PNF exercises was associated with significant improvement in depression scores over a 16-week period in

women with breast cancer-related lymphoedema. Further investigation is necessary, however, as this study did not include a control group for comparison. Another potential intervention that has yet to be evaluated in women with breast cancer-related lymphoedema is the use of psychoeducational support groups and coping skills training (Rockson, 2002). The combination of being able to predict which women are at risk of experiencing psychological distress associated with lymphoedema, combined with identifying effective intervention strategies, has the potential to improve patient outcomes and emotional well-being.

## **Conclusion**

In conclusion, previous research has identified a number of medical and psychosocial factors associated with psychological distress in women living with breast cancer-related lymphoedema. This review found that both qualitative and quantitative studies commonly find that the symptoms of lymphoedema are both directly and indirectly related to psychological distress, along with both patients' and health professionals' knowledge of the illness. However, the question of whether or not lymphoedema is associated with increased psychological distress amongst breast cancer survivors has yet to be resolved. Furthermore, the literature is characterised by critical limitations in study design, methodology and theory. Researchers should aim to address these limitations in the future in order to improve our understanding of psychological distress related to breast cancer-related lymphoedema. It would also be worthwhile to investigate potentially viable intervention strategies for patients. These findings have the potential to help health professionals identify which patients may be at risk for experiencing psychological distress in order to intervene early and provide additional support.

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## **Chapter 5. Distress empirical studies**

This chapter is a collection of the empirical studies conducted on psychological distress in women with breast cancer-related lymphoedema. The first section of this chapter is an article published in a peer-reviewed journal that discusses the analysis of the baseline data from the main, longitudinal study to determine if cognitive and affective factors are associated with psychological distress in accordance with the theoretical framework of this thesis. The second section of this chapter covers the results from the longitudinal data analysis on cognitive and affective predictors of psychological distress in women with breast cancer-related lymphoedema. The final section of this chapter is a manuscript currently under review. It describes the development and user acceptability of an online writing intervention that aims to decrease the psychological distress associated with bodily changes due to breast cancer-related lymphoedema by increasing self-compassion.





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

This section includes a peer-reviewed journal article published in *Psycho-Oncology*. This article discusses the baseline data of the main, longitudinal study that were analysed to determine if cognitive and affective factors were associated with psychological distress (i.e., depression, anxiety and stress) as predicted by the theoretical framework of this thesis. The specific factors investigated include body image disturbance, lymphoedema-related distress, illness beliefs about the controllability and consequences of lymphoedema as well as beliefs about the ability to self-regulate negative affect.

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## 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

## Factors associated with psychological distress

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		t	p	95.0% CI
		B	SE	Beta				
<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 × 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				<0.01		
R <sup>2</sup>		0.24						
Step 2	Age × 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 × 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

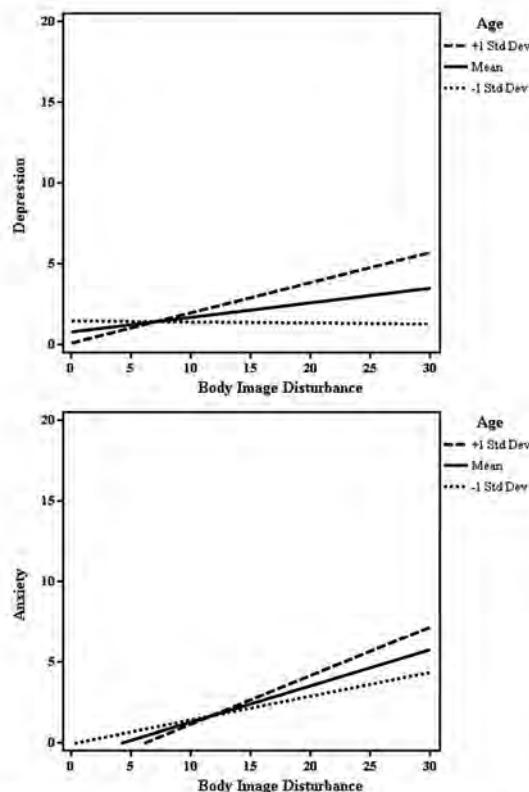
previously documented in the scale validation studies ( $M=8.07$ ,  $SD=5.02$ ) [31],  $t(442)=15.12$ ,  $p<0.001$ , 95% CI [-9.84, -7.58], and in a previous sample of women with breast cancer-related lymphoedema ( $M=12.27$ ,  $SD=8.03$ ) [12],  $t(218)=-4.51$ ,  $p<0.001$ , 95% CI [-6.78, -2.25].

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  $\times$  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,



## Factors associated with psychological distress

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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## **5.2 A longitudinal study of psychological distress, body image disturbance and illness representations in women with breast cancer-related lymphoedema**

Lymphoedema is a chronic, progressive condition characterised by swelling that occurs when protein-rich fluid accumulates in the affected area of the body (Bernas, 2013; Ridner, 2013). Secondary lymphoedema is a common consequence of cancer treatment that involves surgical removal of lymph nodes (Bernas, 2013; Ridner, 2013) or damage to the lymphatic system resulting from radiation therapy (Bernas, 2013; Ridner, 2013; Shah & Vicini, 2011) and possibly chemotherapy (Cariati et al., 2015; Norman et al., 2010; Ridner, 2013). Approximately one in five women treated for breast cancer will develop lymphoedema, with incidence rates higher for those who have undergone more extensive surgery (i.e., axillary-lymph node dissection in comparison to sentinel-node biopsy, greater number of lymph nodes removed) and who are overweight or obese (DiSipio, Rye, Newman, & Hayes, 2013). Women with breast cancer-related lymphoedema may experience severe swelling, tingling, weakness, pain, limited physical mobility, numbness and stiffness (Hayes et al., 2011). These symptoms of lymphoedema can lead to a range of negative psychosocial impacts, including psychological distress (Chachaj et al., 2010; Dominick, Natarajan, Pierce, Madanat, & Madlensky, 2014; Fu et al., 2013; Khan, Amatya, Pallant, & Rajapaksa, 2012; Pyszel, Malyszczak, Pyszel, Andrzejak, & Szuba, 2006).

A previous study found that levels of distress, specifically anxiety, in a sample of women with breast cancer-related lymphoedema were significantly higher than Australian adult population norms (Alcorso & Sherman, 2015). The trajectory of levels of distress in these women is not yet known, however, the oncology literature suggests

that levels of distress decrease in the first year post-cancer and then stabilize over time. For example, in women with breast cancer, previous studies have found that distress tends to decrease during the first 15 months following cancer treatment (Bárez, Blasco, Fernández-Castro, & Viladrich, 2009; Hinnen et al., 2008; Liu, Wang, Wang, Su, & Wang, 2014). This is in comparison to a longitudinal study of colorectal cancer survivors, where levels of distress remained stable over a five year period in the majority (70%) of participants (Dunn et al., 2013). Levels of distress in breast cancer survivors affected by lymphoedema may follow a similar pattern, with distress decreasing post-diagnosis and stabilising over time.

A previous study (Alcorso & Sherman, 2015) found that cognitive and affective factors are associated with psychological distress (i.e., depression, anxiety and stress) in women with breast cancer-related lymphoedema. 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. Beliefs about treatment effectiveness remained significantly associated with distress (stress) in the multivariate analyses. Furthermore, stronger belief in one's ability to self-regulate lymphoedema-related distress was negatively associated with psychological distress in these women. This suggests that women who do not believe they are able to effectively manage their lymphoedema-related distress are at a higher risk of experiencing distress. More broadly, a relationship between cognitive and affective factors and distress has been found in individuals with breast cancer (Fischer et al., 2013; McCorry et al., 2013) and chronic illnesses such as diabetes, asthma and rheumatoid arthritis (Hagger & Orbell, 2003).

Taken together, these findings are consistent with the Common Sense Model (CSM) of illness self-regulation (Diefenbach & Leventhal, 1996; Leventhal, Leventhal,

& Contrada, 1998; Leventhal, Meyer, & Nerenz, 1980) and the Cognitive-Social Health Information Processing (C-SHIP) model (Miller & Diefenbach, 1998). These social cognitive models predict that cognitive and affective illness representations are associated with physical and emotional patient outcomes. The CSM proposes that individuals' illness representations, including cognitive beliefs about their illness (e.g., beliefs about the controllability of an illness) and affective responses to their illness (e.g., anger or distress), influence their chosen coping strategies (e.g., actively seeking social support or avoidance and withdrawal) (Hagger & Orbell, 2003). The CSM also explains how an individual's ability to evaluate the outcomes of her chosen coping strategies forms a self-regulatory feedback loop that continues to influence her beliefs, affect and future behaviour (Diefenbach & Leventhal, 1996; Hagger & Orbell, 2003).

The C-SHIP predicts further that cognitive and affective factors (e.g., illness representations, illness-related affect and self-regulatory ability) mediate the relationship between health information and an individual's subjective response (Miller, Shoda, & Hurley, 1996). For example, women with mild, Stage 1 lymphoedema (health information) may not believe that lymphoedema has negative consequences in their lives (illness representation) and consequently these women may not have high levels of distress (depression, anxiety and stress). In comparison, women with more advanced lymphoedema may believe strongly in the negative consequences of lymphoedema and subsequently experience distress. Thus, the relationship between health information, such as a woman's stage of lymphoedema, and distress may be mediated by cognitive and affective factors.

Another significant contributor to psychological distress in women with breast cancer-related lymphoedema is body image disturbance (Alcorso & Sherman, 2015; Chachaj et al., 2010; Fu et al., 2013; Teo, Novy, Chang, Cox, & Fingeret, 2015).

Lymphoedema can cause significant bodily appearance changes due to extensive and visibly noticeable swelling in the chest and/or arm which also affects a woman's choice of clothing (e.g., being unable to wear slim fitting clothes) (Fu et al., 2013; Rhoten, Radina, Adair, Sinclair, & Ridner, 2015). In several qualitative studies (Fu & Rosedale, 2009; Heppner et al., 2009; Ridner, Bonner, Deng, & Sinclair, 2012) women with breast cancer-related lymphoedema have reported body image difficulties as a source of distress. Moreover, two quantitative studies have found that body image disturbance is associated with distress. In one study (Teo et al., 2015), body image disturbance mediated the relationships between pain and body integrity beliefs, and pain and depression, in women with breast cancer-related lymphoedema. Another study (Alcorso & Sherman, 2015) found that body image disturbance was a significant predictor of depression, anxiety and stress in multivariate analyses that included age, number of symptoms and illness beliefs (i.e., controllability of lymphoedema, perceived treatment effectiveness, negative consequences of lymphoedema and beliefs about one's ability to self-regulate negative affect). An interesting finding from this study was that older women experienced more psychological distress associated with body image disturbance in comparison to younger women (Alcorso & Sherman, 2015), contrary to prior research that has reported that younger breast cancer survivors experienced greater body image disturbance, and subsequently greater psychological distress (Przedziecki et al., 2013). Although younger women with breast cancer have generally reported significantly greater body image disturbance compared with older women (Avis, Crawford, & Manuel, 2004; Fobair et al., 2006), yet this body image disturbance has not typically been associated with increased distress in the younger women, compared with older women.

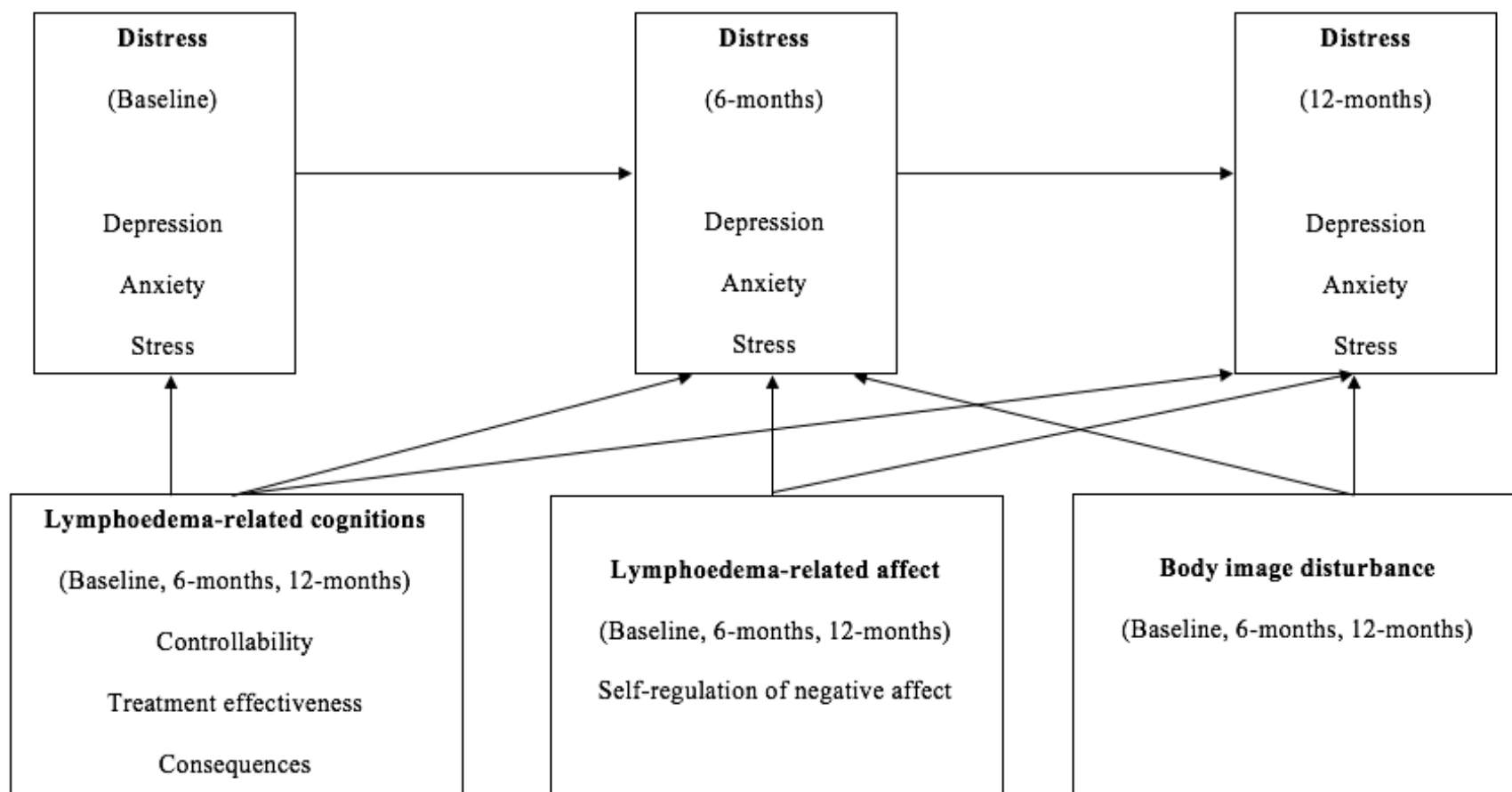
There were five aims of this study. The primary aim of this study was to examine the trajectory of distress (depression, anxiety and stress) over a period of 12 months in women with breast cancer-related lymphoedema. Given that we were not following women during the initial post-diagnosis stage, we predicted that levels of distress would remain stable over time (Dunn et al., 2013).

The second aim of this study was to examine the trajectory of cognitive and affective factors (i.e., lymphoedema-related cognitions, lymphoedema-related affect and body image disturbance) over a period of 12 months. No known study has measured these factors over time in a population of women with breast cancer-related lymphoedema; however, one study measured cognitive and affective factors soon after breast cancer diagnosis for a period of 12 months in a sample of women at-risk of developing lymphoedema (Sherman, Miller, Roussi, & Taylor, 2015). In this study, the only factor that changed over time was beliefs in the self-regulatory ability to manage negative affect, which significantly increased from baseline to 12 months. Thus, we predicted that for women with breast cancer-related lymphoedema, beliefs in the self-regulatory ability to manage negative affect would increase over time, while other cognitive and affective factors would remain stable.

The third aim of this study was to identify cognitive and affective predictors of distress (see Figure 5.2.1). Pervious cross-sectional studies have identified a correlation between illness representations and self-regulation of affect and distress (Alcorso & Sherman, 2015) and body image disturbance and distress (Alcorso & Sherman, 2015; Teo et al., 2015) in women with breast cancer-related lymphoedema. These findings are consistent with the broader oncology literature: in colorectal cancer survivors, body image disturbance predicted distress (specifically, anxiety and depression)







**Figure 5.2.1** Conceptual model of the study’s primary and secondary aims: (1) To determine the trajectory of distress over a 12-month period, and (2) to identify cognitive and affective predictors of distress.



(Sharpe, Patel, & Clarke, 2011), and in breast cancer survivors illness representations predicted distress (Millar, Purushotham, McLatchie, George, & Murray, 2005). Thus, predicted that higher body image disturbance, greater beliefs in the negative consequences of lymphoedema and lower beliefs in the controllability of lymphoedema, treatment effectiveness and the ability to self-regulate negative affect would predict distress at 6-months and 12-months.

The fourth aim of this study was to identify mediators of the relationship between lymphoedema stage (i.e., reflecting awareness and information about that specific condition and health threats) and distress. In accordance with the C-SHIP model (Miller et al., 1996), we predicted that the cognitive and affective factors would mediate the relationship between health status information/awareness (lymphoedema stage) and distress (depression, anxiety and stress). Finally, this study aimed to replicate the finding of a moderating effect of age on the relationship between body image disturbance and distress (Alcorso & Sherman, 2015).

## **Method**

### **Participants and procedure**

English-speaking adult (18+years) women who were previously diagnosed with breast cancer-related lymphoedema were eligible to participate in the study. Following approval from the Macquarie University Human Ethics Review Committee, women were recruited through a community-based breast cancer organisation, the Breast Cancer Network Australia, and three lymphoedema treatment clinics located in Sydney, Australia. Respondents from the Breast Cancer Network Australia (BCNA) were recruited by email invitation that was sent to approximately 2000 breast cancer-affected members interested in research participation. It is not possible to know with certainty

how many of the women in the general pool from the BCNA were affected with breast cancer-related lymphoedema. However, approximately 20% of all women with invasive breast cancer subsequently develop lymphoedema (DiSipio et al., 2013); therefore, we anticipated that up to 400 of the BCNA research pool members would have been affected with lymphoedema. On this basis, the 170 women recruited from the BCNA research pool represent an estimated 43% response rate. Respondents from the lymphoedema clinics ( $n = 30$ ; response rate 28.8%) were invited directly by clinic therapists through an invitational letter that provided the web address to access the online questionnaire. Participants completed three online questionnaires (baseline, 6- and 12-months) assessing demographic information and medical history (at baseline only), cognitive and affective factors, and distress. Each questionnaire was estimated to take 20 min to complete and participants received a \$5 coffee voucher for each follow-up questionnaire completed (maximum \$10 compensation for completing all three questionnaires).

## Measures

**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 seven 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 ( $\alpha = .92$ ), Anxiety ( $\alpha = .79$ ), and Stress ( $\alpha = .84$ ).

**Lymphoedema-related cognitions.** Beliefs about the controllability, perceived treatment effectiveness 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 (5 items, possible range 5–25;  $\alpha = 0.79$ ) and Consequences (6 items, possible range 5–30;  $\alpha = 0.88$ ) subscales was satisfactory.

**Lymphoedema-related affect.** 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;  $\alpha = .81$ ). 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 breast cancer patients 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 (1 = not at all, 4 = very much). Item scores were summed (possible range 0–30;  $\alpha = .94$ ), with higher total scores indicating greater body image disturbance.

**Demographics, medical history and health economic variables.** Demographic information collected included age, Australian Aboriginal or Torres Strait Islander status, education level, income, marital status, and employment status. Participants provided information about their medical history including details about their breast cancer treatment (i.e., lymph node surgery type, chemotherapy, radiation therapy and hormone replacement therapy), lymphoedema (i.e., time since diagnosis, stage, current treatment, symptoms), and whether or not they have any comorbid conditions.

Lymphoedema stage was measured at baseline only, as previous research suggests that even untreated lymphoedema progresses to higher stages over a duration of years and not within a period of 12 months (Casley-Smith, 1995). Health economic variables measured included whether or not the participant received subsidised treatment (i.e., by having an Enhanced Primary Care plan or compression garment subsidy scheme), if she had private health insurance, and an estimation of her annual out-of-pocket costs for lymphoedema treatment.

## **Data analysis**

**Descriptive statistics and identifying covariates.** Descriptive statistics were calculated for participant demographic, medical history and health economic characteristics. Independent samples *t*-tests and chi-square analyses were conducted on baseline characteristics to compare participants in the final sample with participants lost to follow-up. Independent samples *t*-tests and one-way ANOVAs (categorical variables) and Pearson (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 health economic variables at baseline to identify potential covariates. Variables associated with depression, anxiety or stress at  $p < 0.100$  were included as covariates in subsequent analyses.

**Change in distress over time and predictors of distress.** Maximum-likelihood linear mixed models were used to determine: (1) if levels of distress changed over time and (2) if cognitive and affective variables predicted distress at each assessment point. A linear mixed models approach was chosen due to its flexibility and power for analysing longitudinal data (Avilés, 2001). Linear mixed models are particularly useful for maximizing the number of data points included in an analysis for datasets with missing values. Furthermore, mixed models provide a reliable estimate of change in variables over time by accounting for variability among participants over time (Avilés, 2001). Data analyses accounted for both time-varying and subject-based (i.e., measured at baseline only) variables. Fixed effects included time and identified covariates. Random effects for a participant-specific random intercept accounted for within-participant correlation.

First, separate analyses were undertaken to determine if levels of distress (depression, anxiety and stress) changed over time. Next, each cognitive and affective variable was tested as predictors of distress. The critical  $p$  value for the predictor variables was reduced from 0.05 to 0.008 to adjust for the multiple analyses (six predictor variables) in accordance with the Bonferonni correction method. All analyses were carried out using SPSS (Version 21, Armonk, NY: IBM Corp).

**Mediation analysis.** A series of mediation analyses were conducted to determine if the cognitive and affective factors at 6-months mediated the relationship between lymphoedema stage at baseline and the distress outcome variables (depression,

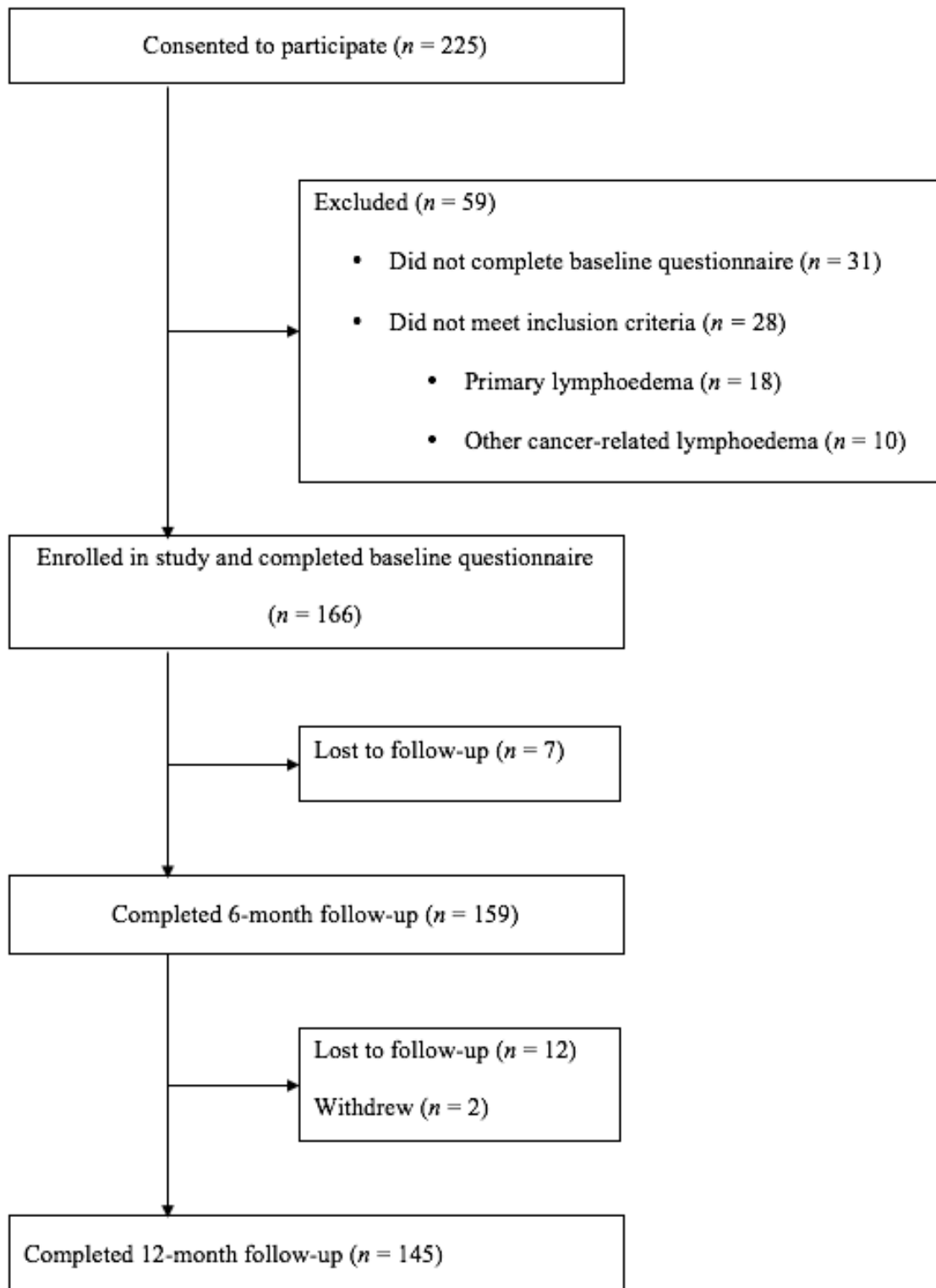
anxiety and stress) at 12-months. The Preacher and Hayes (Preacher & Hayes, 2008) method was used to test mediation. This method uses bootstrapping to estimate the significance of indirect effects. Bootstrapped samples are drawn from the data to estimate the indirect effect for each mediator. The Hayes PROCESS macro (Hayes, 2013) with 1,000 bias-corrected bootstrapping resamples and 95% confidence intervals for each of the indirect effects calculated.

**Moderation analysis.** The mixed models approach was also used to determine if age moderated the relationship between body image disturbance and distress. Fixed effects included time and identified covariates, and random effects for a participant-specific random intercept accounted for within-participant correlation. The interaction of body image disturbance x age was tested as a predictor of distress (depression, anxiety and stress).

## Results

A total of 200 individuals consented to participate in the study, and the final analysable sample of  $n = 166$  remained at baseline after removing incomplete data ( $n = 34$ ). Following the baseline questionnaire data collection, seven participants at six-months and a further 14 participants at 12-months were lost to follow-up, leaving 145 participants who completed all three questionnaires (87.3% retention) (See Figure 5.2.2 for a diagram of participant progress through this study). Participant baseline characteristics and between-subject comparisons for participants that completed all three questionnaires (final sample) and individuals lost to follow-up are displayed in Table 5.2.1. The group of participants in the final sample and the group of participants lost to follow-up were similar across all characteristics except employment status,  $\chi^2 = (3, N = 166) = 17.40, p = .015$ .





**Figure 5.2.2** Participant progress through each phase of the study.

**Change in distress over time.** Descriptive statistics for the distress outcome variables at baseline, 6-months and 12-months are reported in Table 5.2.2. DASS-21 anxiety scores for this sample ( $2.76$ ,  $SD = 3.35$ ) were significantly higher than for the Australian adult population norm ( $1.74$ ,  $SD = 2.78$ ) (Crawford, Cayley, Lovibond, Wilson, & Hartley, 2011),  $t(640) = 3.70$ ,  $p < 0.001$ , 95% CI [0.46, 1.55]. Scores on the Depression  $t(640) = 1.46$ ,  $p = 0.114$ , and Stress  $t(40) = 1.25$ ,  $p = 0.213$ , subscales for this sample did not differ from Australian norms (Crawford et al., 2011). Overall, there was no significant change over time for depression,  $F(2, 283) = 2.45$ ,  $p = 0.088$ , nor anxiety,  $F(2, 284) = 1.60$ ,  $p = 0.203$ , scores. In contrast, there was a significant increase in stress scores from baseline to 12-months,  $F(2, 284) = 13.31$ ,  $p < 0.001$ .

**Identifying covariates.** Three medical history and health economic variables were identified as covariates to be included in the subsequent mixed model analyses: lymphoedema stage, number of symptoms and out-of-pocket costs. Women with more severe lymphoedema had higher levels of depression ( $r = 0.22$ ,  $p = 0.007$ ), anxiety ( $r = 0.18$ ,  $p = 0.035$ ) and stress ( $r = 0.17$ ,  $p = 0.043$ ). Similarly, women reporting a greater number of lymphoedema symptoms had higher levels of depression ( $r = 0.32$ ,  $p < 0.001$ ), anxiety ( $r = 0.24$ ,  $p < 0.001$ ) and stress ( $r = 0.23$ ,  $p < 0.001$ ). Women reporting higher out-of-pocket costs for lymphoedema treatment and management also had higher levels of depression ( $r = 0.19$ ,  $p = 0.024$ ), anxiety ( $r = 0.16$ ,  $p = 0.066$ ) and stress ( $r = 0.22$ ,  $p = 0.009$ ).

**Change in cognitive and affective variables over time.** Descriptive statistics for the cognitive and affective variables at baseline, 6-months and 12-months are displayed in Table 5.2.2. Beliefs about the personal controllability of lymphoedema significantly increased over time, -  $F(2, 286) = 293.86$ ,  $p < 0.001$ , increasing from baseline to 6-months ( $p < 0.001$ ) and from 6-months to 12-months ( $p < 0.001$ ). Beliefs

**Table 5.2.1** Participant characteristics at baseline.

Variable	Withdrew / Lost		Between group comparisons <i>t</i> or $\chi^2$ , <i>p</i>	Association with distress at baseline		
	Final sample <i>n</i> = 145	to follow-up <i>n</i> = 21		<i>p</i>		
	<i>M</i> ( <i>SD</i> ) or %	<i>M</i> ( <i>SD</i> ) or %		Depression	Anxiety	Stress
Age (years)	58.04 (10.62)	58.67 (11.83)	$t(166) = 0.56, p = .576$	0.988	0.670	0.663
Australian Aboriginal or Torres Strait Islander (%)	2.0	14.3	$\chi^2 (1, N = 166) = 10.63, p = .014$	0.886	0.459	0.556
Education (%)			$\chi^2 = (2, N = 166) = 9.56, p = .215$	0.315	0.325	0.522
High school or less	22.9	42.9				
Some tertiary	38.6	28.6				
Tertiary degree or more	38.5	28.5				
Income (%)			$\chi^2 = (3, N = 166) = 7.58, p = .751$	0.276	0.254	0.728
Less than \$50,000	29.1	31.3				
\$50,001 - \$100,000	40.4	43.7				
\$100,001 – \$150,000	19.2	12.5				
More than \$150,000	11.3	12.5				
Marital status (%)			$\chi^2 = (3, N = 166) = 3.55, p = .470$	0.370	0.962	0.438
Married/partnered	79.9	76.2				
Divorced/separated	8.3	4.8				

Variable	Withdrawn / Lost		Between group comparisons <i>t</i> or $\chi^2, p$	Association with distress at baseline		
	Final sample <i>n</i> = 145	to follow-up <i>n</i> = 21		<i>p</i>		
	<i>M</i> ( <i>SD</i> ) or %	<i>M</i> ( <i>SD</i> ) or %		Depression	Anxiety	Stress
Single	7.1	9.5				
Widowed	4.1	9.5				
Employment status (%)			$\chi^2 = (3, N = 166) = 17.40, p = .015$	0.233	0.507	0.419
Full time	30.8	47.6				
Part time	23.7	9.5				
Retired	35.5	42.9				
Unemployed	10.0	0.0				
Type of lymph node surgery (%)			$\chi^2 = (1, N = 166) = 1.06, p = .588$	0.815	0.790	0.706
Sentinel node	10.7	14.3				
Axillary	62.7	52.4				
I do not know	26.6	33.3				
Received chemotherapy (%)	79.9	90.5	$\chi^2 = (1, N = 166) = 1.71, p = .191$	0.955	0.463	0.807
Received radiation (%)	76.9	76.2	$\chi^2 = (1, N = 166) = 0.01, p = .945$	0.681	0.121	0.399
Received hormone	29.6	28.6	$\chi^2 = (1, N = 166) = 0.01, p = .945$	0.348	0.240	0.575

Variable	Withdrawn / Lost		Between group comparisons <i>t</i> or $\chi^2, p$	Association with distress at baseline		
	Final sample <i>n</i> = 145	to follow-up <i>n</i> = 21		<i>p</i>		
	<i>M</i> ( <i>SD</i> ) or %	<i>M</i> ( <i>SD</i> ) or %		Depression	Anxiety	Stress
replacement therapy (%)						
Time since lymphoedema diagnosis (years)	5.54 (5.49)	5.24 (4.77)	$t(166) = -0.29, p = .777$	0.688	0.725	0.301
Lymphoedema Stage (%)			$\chi^2 = (4, N = 166) = 7.54, p = .110$	0.007	0.035	0.043
Stage 0 (Subclinical)	17.8	0.0				
Stage 1 (Mild)	58.6	73.6				
Stage 2 (Moderate)	21.7	21.1				
Stage 3 (Severe)	1.3	5.3				
I do not know	0.6	0.0				
Lymphoedema treatment (%)						
Bandaging	27.4	42.9	$\chi^2 = (1, N = 166) = 2.89, p = .089$	.802	.839	.791
Manual lymphatic drainage	69.6	61.9	$\chi^2 = (1, N = 166) = 0.68, p = .410$	.734	.633	.690
Surgery	0.0	0.0				
Laser	7.8	9.5	$\chi^2 = (1, N = 166) = 0.31, p = .575$	.629	.931	.941
Number of lymphoedema	5.45 (2.41)	4.67 (2.52)	$t(166) = -0.99, p = .323$	<0.001	0.002	0.003

Variable	Withdrawn / Lost		Between group comparisons <i>t</i> or $\chi^2, p$	Association with distress at baseline		
	Final sample <i>n</i> = 145	to follow-up <i>n</i> = 21		<i>p</i>		
	<i>M</i> ( <i>SD</i> ) or %	<i>M</i> ( <i>SD</i> ) or %		Depression	Anxiety	Stress
symptoms						
Comorbid chronic conditions(s) (%)						
Diabetes Type 1	0.6	0.0	$\chi^2 = (1, N = 166) = 0.15, p = .696$	.668	.600	.702
Diabetes Type 2	3.1	0.0	$\chi^2 = (1, N = 166) = 0.79, p = .375$	.884	.608	.270
Coronary heart disease	1.9	4.8	$\chi^2 = (1, N = 166) = 1.08, p = .299$	.351	.748	.860
Stroke	0.0	0.0				
Asthma	15.1	4.8	$\chi^2 = (1, N = 166) = 2.02, p = .156$	.857	.567	.704
Chronic Obstructive Pulmonary Disease	0.0	0.0				
Chronic Kidney Disease	0.6	0.0	$\chi^2 = (1, N = 166) = 0.15, p = .696$	.799	.600	.702
None	78.7	81.0	$\chi^2 = (1, N = 166) = 0.01, p = .982$	.341	.512	.575
Enhanced Primary Care Plan (%)	26.8	42.1	$\chi^2 = (1, N = 166) = 2.6, p = .272$	0.564	0.434	0.635
Private Health Insurance	61.1	73.7	$\chi^2 = (1, N = 166) = 1.44, p = .487$	0.794	0.762	0.149

Variable	Withdrawn / Lost		Between group comparisons <i>t</i> or $\chi^2, p$	Association with distress at baseline		
	Final sample <i>n</i> = 145	to follow-up <i>n</i> = 21		<i>p</i>		
	<i>M</i> ( <i>SD</i> ) or %	<i>M</i> ( <i>SD</i> ) or %		Depression	Anxiety	Stress
(%)						
Compression garment	18.5	21.1	$\chi^2 = (1, N = 166) = 0.49, p = .782$	0.210	0.152	0.744
subsidy scheme (%)						
Out of pocket			$\chi^2 = (4, N = 166) = 2.84, p = .829$	0.024	0.066	0.009
lymphoedema treatment						
costs (%)						
\$0 - \$500	56.3	73.2				
\$501 - \$1,000	19.3	6.7				
\$1,001 - \$1,500	9.3	6.7				
\$1,501 - \$2,000	8.0	6.7				
More than \$2,000	7.1	6.7				

\*. Correlation is significant at the 0.05 level (2-tailed).





about the negative consequences of lymphoedema significantly increased over time,  $F(2, 284) = 129.36, p < 0.001$ , increasing from baseline to 6-months ( $p < 0.001$ ) and from 6-months to 12-months ( $p < 0.001$ ). Body image disturbance increased significantly from baseline to 12-months ( $p < 0.001$ ), but did not change significantly between each time point,  $F(2, 283) = 6.44, p = 0.002$ . The mean BIS score (17.06,  $SD = 7.29$ ) was significantly higher than previously documented in the scale validation studies (8.07,  $SD = 5.02$ ) (Hopwood, Fletcher, Lee, & Al Ghazal, 2001),  $t(825) = 14.24, p < 0.001$ , 95% CI [8.12, 10.72], and in a previous sample of women with breast cancer-related lymphoedema (12.27,  $SD = 8.03$ ) (Teo et al., 2015),  $t(197) = 4.01, p < 0.001$ , 95% CI [2.43, 7.15].

**Cognitive and affective predictors of distress.** Greater body image disturbance was a significant predictor of depression,  $F(1,407) = 113.81, p < 0.001$ , anxiety,  $F(1,409) = 53.28, p < 0.001$ , and stress scores,  $F(1,396) = 31.45, p < 0.001$ . Greater beliefs in the negative consequences of lymphoedema significantly predicted higher scores for depression,  $F(1,401) = 12.33, p < 0.001$ , anxiety,  $F(1, 403) = 8.88, p = 0.003$ , and stress,  $F(1, 410) = 4.92, p = 0.027$ . Greater beliefs in the self-regulatory ability to manage lymphoedema-related negative affect was also a significant predictor of depression,  $F(1, 342) = 12.04, p = 0.001$ , anxiety,  $F(1,347) = 10.70, p = 0.001$ , and stress scores,  $F(1,356) = 10.92, p = 0.001$ . In addition, beliefs in the personal controllability of lymphoedema was a significant predictor of anxiety,  $F(1,302) = 12.07, p = 0.001$ .

**Mediation analyses.** The cognitive and affective predictors of distress (i.e., consequences, self-regulation of affect, beliefs about the personal controllability of lymphoedema and body image disturbance) at the 6-month time point were tested as mediators of the relationship between lymphoedema stage at baseline and distress



**Table 5.2.2** Descriptive statistics and change over time for the outcome variables (depression, anxiety and stress) and predictor variables.

Variable	Range	Baseline <i>M (SD)</i>	6 Months <i>M (SD)</i>	12 Months <i>M (SD)</i>	Change over		Predictive of		Predictive of		Predictive of	
					time		depression?		anxiety?		stress?	
					<i>F</i>	<i>p</i>	<i>F</i>	<i>p</i>	<i>F</i>	<i>p</i>	<i>F</i>	<i>p</i>
Depression	0 – 21	3.12 (4.38)	3.29 (3.86)	3.52 (4.1)	2.45	0.088	-	-	-	-	-	-
Anxiety	0 – 21	2.76 (3.35)	2.91 (3.20)	3.07 (3.70)	1.60	0.205	-	-	-	-	-	-
Stress	0 – 21	4.48 (3.89)	5.02 (3.71)	5.63 (4.49)	13.31	<b>&lt;0.001</b>	-	-	-	-		-
Symptoms	0 – 10	5.23 (2.41)	5.81 (2.81)	4.98 (2.53)	11.16	<b>&lt;0.001</b>	2.88	0.091	1.38	0.241	0.01	0.965
Personal control	6 – 30	16.26 (2.27)	19.94 (1.77)	23.60 (3.78)	293.86	<b>&lt;0.001</b>	0.22	0.641	12.07	<b>0.001</b>	0.94	0.333
Perceived treatment effectiveness	5 – 25	16.24 (3.21)	16.34 (1.94)	16.54 (3.17)	0.55	0.580	1.79	0.182	2.63	0.106	0.03	0.875
Consequences	6 – 30	15.46 (3.22)	17.12 (3.38)	18.79 (4.31)	129.36	<b>&lt;0.001</b>	12.33	<b>&lt;0.001</b>	8.88	<b>0.003</b>	4.92	<b>0.027</b>
Self-regulation of affect	2 – 10	7.71 (1.42)	7.54 (1.74)	7.78 (1.55)	1.85	0.159	12.04	<b>0.001</b>	10.70	<b>0.001</b>	10.92	<b>0.001</b>
Body image disturbance	10 – 40	17.06 (7.29)	17.63 (6.90)	18.21 (7.51)	6.44	<b>0.002</b>	113.81	<b>&lt;0.001</b>	53.28	<b>&lt;0.001</b>	31.45	<b>&lt;0.001</b>

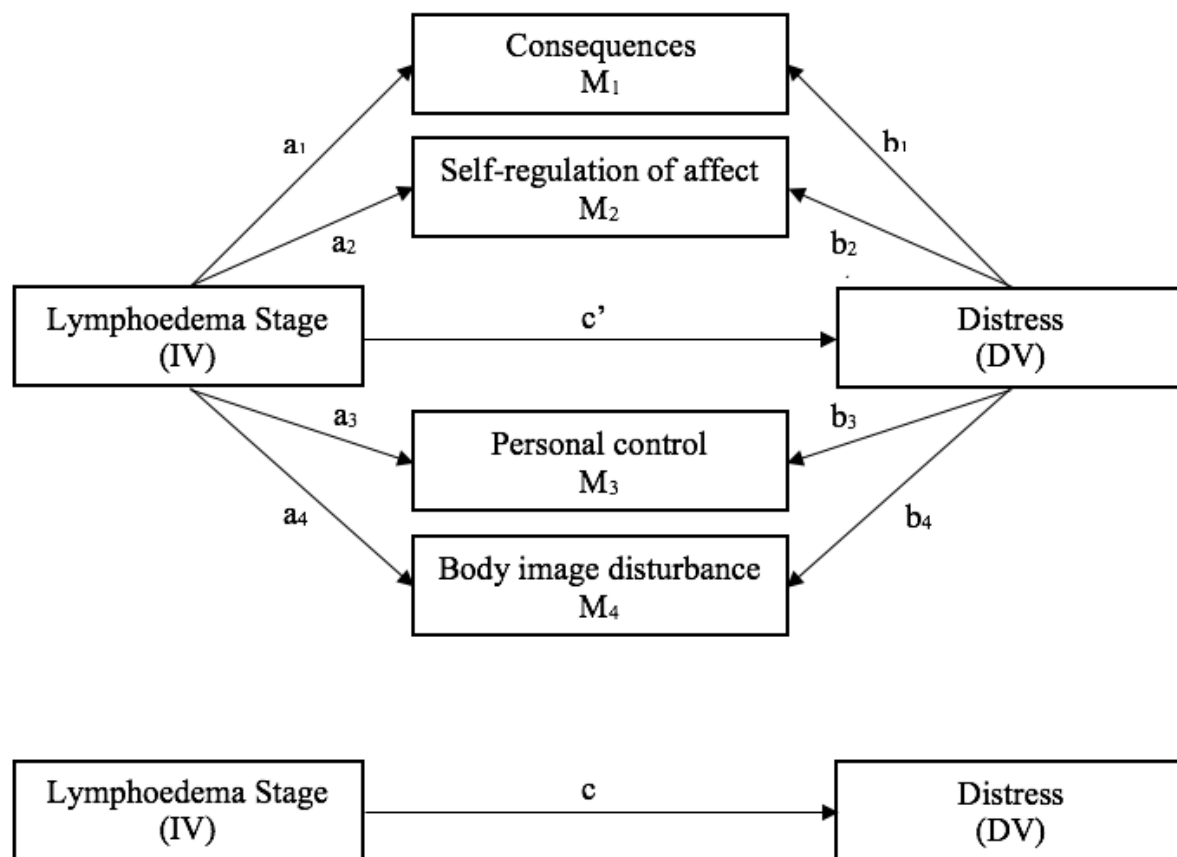


(depression, anxiety and stress) at 12-months (see Figure 5.2.3). Results of the analyses and tests of potential mediating variables are displayed in Table 5.2.3, with number of symptoms and out-of-pocket costs as covariates. Beliefs about the negative consequences of lymphoedema was found to be a significant mediator for depression, 95% CI [0.16, 1.02], and anxiety, 95% CI [0.09, 0.74] such that women with more advanced lymphoedema had stronger beliefs in the negative consequences of lymphoedema and subsequently higher levels of distress. Body image disturbance was found to be a significant mediator for depression, 95% CI [0.02, 0.07], anxiety, 95% CI [0.03, 0.06], and stress, 95% CI [0.01, 0.04] such that women with more advanced lymphoedema had higher levels of body image disturbance and subsequently higher levels of distress.

**Moderation analyses.** The body image disturbance x age interaction was not significant for depression,  $F(1, 370) = 0.87, p = 0.351$ , anxiety,  $F(1, 372) = 0.17, p = 0.682$ , or stress,  $F(1, 350) = 0.10, p = 0.756$ .

## Discussion

This study was the first to measure the trajectory of distress, lymphoedema-related illness representations and body image disturbance in women with breast cancer-related lymphoedema over a period of 12 months. Psychological distress levels did change over time, contrary to expectation. Specifically, stress (i.e., indicating levels of chronic, non-specific arousal) increased over time, with a non-significant trend for increases in both depression and anxiety. This finding conflicts with previous research in oncology. In women with breast cancer, previous studies have found that distress tends to decrease over time for most women within the first 15 months following cancer treatment (Bárez et al., 2009; Hinnen et al., 2008; Liu et al., 2014). In a sample of men



**Figure 5.2.3** Graphic representation of the mediation model.

and women with colorectal cancer, distress levels remained stable over a period of five years for the majority of participants (Dunn et al., 2013). The distress reported in women with breast cancer-related lymphoedema in the present study suggests that the experiences of individuals with cancer-related lymphoedema may follow a different trajectory than that of other cancer survivors due to the daily challenges of living with lymphoedema. For example, cancer survivors without lymphoedema do not have to practice daily self-care or wear a compression garment. The ongoing burdens of lymphoedema may contribute to increased distress over time, especially if women are struggling with maintaining a regular self-care regimen. It is important to note that levels of anxiety in this sample were significantly higher in comparison to Australian adult population norms (Crawford et al., 2011). Health professionals treating women with lymphoedema should be aware that some women with breast cancer-related lymphoedema have high levels of distress that remain high over time, and that it is important provide appropriate psychological support and intervention for these women whose distress is not resolving. Referral to a mental health professional in this instance may be warranted.

Contrary to prediction, there were some significant changes in the cognitive variables over the 12-month study period. Beliefs about the personal controllability of lymphoedema and the negative consequences of lymphoedema increased significantly over time. This is in contrast to findings from a sample of women at-risk of breast cancer-related lymphoedema, where similar cognitive factors (e.g., beliefs about the consequences of lymphoedema and perceived risk) remained stable over time (Sherman et al., 2015). It is not clear why these factors changed over time. Future studies should aim to identify what factors influence changes in beliefs about the consequences and controllability of lymphoedema. Levels of body image disturbance also increased over





**Table 5.2.3** Tests of the potential mediating variables.

	Effect of IV on		Effect of MV on		Direct effect		Total effect		Indirect effect		95% CI	
	MV		DV		(c' path) <sup>a</sup>		(c path) <sup>a</sup>		(a x b)			
	(a path)		(b path)									
	$\beta$	<i>p</i>	$\beta$	<i>p</i>	$\beta$	<i>p</i>	$\beta$	<i>p</i>	$\beta$	SE	Lower	Upper
<i>Depression</i>												
Consequences	1.30	0.001	0.39	<0.001	0.78	0.103	1.29	0.008	0.51	0.22	0.16	1.02
Self-regulation of affect	-0.33	0.122	-0.95	<0.001	1.07	0.019	1.39	0.005	0.31	0.24	-0.10	0.86
Personal control	-0.51	0.016	0.13	0.457	0.13	0.457	0.91	0.039	-0.07	0.11	-0.40	0.13
Body image disturbance	0.99	<0.001	0.04	<0.001	-0.01	0.886	0.04	0.008	0.04	0.01	0.02	0.07
<i>Anxiety</i>												
Consequences	1.30	0.001	0.28	0.004	0.55	0.213	0.91	0.039	0.36	0.16	0.09	0.74
Self-regulation of affect	-0.33	0.122	-0.76	<0.001	0.67	0.114	0.92	0.041	0.25	0.20	-0.08	0.68
Personal control	-0.51	0.016	0.13	0.457	0.13	0.457	0.91	0.039	-0.07	0.11	-0.40	0.13
Body image disturbance	0.76	<0.001	0.04	<0.001	-0.01	0.783	0.03	0.036	0.03	0.01	0.02	0.06
<i>Stress</i>												
Consequences	1.30	0.001	0.34	0.003	-0.19	0.722	0.23	0.633	0.45	0.21	0.09	0.90
Self-regulation of affect	-0.33	0.122	-0.89	<0.001	0.04	0.935	0.33	0.543	0.29	0.23	-0.10	0.81
Personal control	-0.51	0.016	0.13	0.457	0.13	0.457	0.91	0.039	-0.07	0.11	-0.40	0.13

	Effect of IV on MV (a path)		Effect of MV on DV (b path)		Direct effect (c' path) <sup>a</sup>		Total effect (c path) <sup>a</sup>		Indirect effect (a x b)		95% CI	
Body image disturbance	0.48	<0.001	0.04	<0.001	-0.02	0.131	0.03	0.036	0.02	0.01	0.01	0.04

*Note:* IV, lymphedema stage; MV, moderating variable; DV, distress; CI, confidence interval.

<sup>a</sup>The total and direct effects were for the single independent variable in each model.

time. One explanation for this finding is that the women in this study reported experiencing a worsening of symptoms (e.g., swelling) throughout the duration of the study, and they subsequently may have become more preoccupied with the negative changes to their body caused by lymphoedema.

Cross-sectional studies have found a link between illness representations and self-regulation of affect and distress (Alcorso & Sherman, 2015), and body image disturbance and distress (Alcorso & Sherman, 2015; Teo et al., 2015) in women with breast cancer-related lymphoedema. Furthermore, body image disturbance (Sharpe et al., 2011) and illness representations (Millar et al., 2005) have predicted distress in other oncology populations. However, this was the first study to examine these factors as predictors of distress in the lymphoedema context. In the mixed model analyses, body image disturbance, beliefs in the negative consequences of lymphoedema, and beliefs in the ability to self-regulate negative affect were significant predictors of depression, anxiety and stress. Furthermore, beliefs in the personal controllability of lymphoedema significantly predicted anxiety.

The finding that body image disturbance was a significant predictor of distress extends the earlier cross-sectional work in lymphoedema specifically (Alcorso & Sherman, 2015), and breast cancer more broadly (Przedziecki et al., 2013), that has identified a link between body image disturbance and distress. In the literature on breast cancer-related lymphoedema, body image disturbance and related distress has been well documented in both qualitative (Fu et al., 2013; Radina, Fu, Horstman, & Kang, 2015; Rhoten et al., 2015) and quantitative studies (Fu et al., 2013; Teo et al., 2015). The swelling caused by lymphoedema is visible and also requires a compression garment to be worn on the arm, hand and/or breast (Merchant & Chen, 2015). Women report how the swelling and garments make them feel unattractive and negatively impact

clothing choice (Fu et al., 2013; Heppner et al., 2009; Honnor, 2009; Passik & McDonald, 1998; Radina, Watson, & Faubert, 2008; Ridner, 2009). In the case of breast cancer-related lymphoedema, it is also important to consider how the negative changes in appearance caused by lymphoedema may have a compounding effect on distress when combined with the bodily changes caused by breast cancer treatment (Avis et al., 2004; Fobair et al., 2006; Schover et al., 1995). Indeed, women in this study had significantly higher levels of body image disturbance in comparison to breast cancer patients without lymphoedema (Hopwood et al., 2001). Body image disturbance in this study was also significantly higher in comparison to a previous study of women with breast cancer-related lymphoedema (Teo et al., 2015), in which all participants had undergone surgical treatment for lymphoedema. It is possible that surgical 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.

In comparison to the relationship between body image disturbance and distress in the lymphoedema context, other cognitive and affective factors have received relatively limited research attention. This study found that greater beliefs in the negative consequences of lymphoedema predicted higher levels of distress in women with breast cancer-related lymphoedema, whereas greater beliefs in the personal controllability of lymphoedema predicted lower levels of distress (anxiety only). That is, women who believed more strongly that lymphoedema has negative consequences in their lives and that they have little control over their lymphoedema had higher levels of distress. These findings are consistent with studies in women with breast cancer (Báñez et al., 2009; McCorry et al., 2013; Rees, Fry, Cull, & Sutton, 2004) as well as with the chronic disease literature more generally (e.g., diabetes, chronic fatigue syndrome, asthma and rheumatoid arthritis; Hagger & Orbell, 2003; Paddison, Alpass, & Stephens, 2010).

These findings can be explained by the relationship between illness beliefs, coping strategies and outcomes. A meta-analysis (Hagger & Orbell, 2003) found that greater beliefs in the perceived controllability of an illness is associated with active coping (i.e., problem-focused coping – directly addressing the problems related to the illness) and cognitive reappraisal (i.e., acknowledging the presence of an illness but choosing to see the problem differently). On the other hand, greater beliefs in the negative consequences of an illness were associated with avoidance/denial. If women believe more strongly that lymphoedema has negative consequences and that they have little control over their lymphoedema, then it is possible that they are not engaging in effective coping strategies. Indeed, in this study, beliefs in the negative consequences of lymphoedema was identified as a mediator of the relationship between a woman's stage of lymphoedema and distress, such that women with more advanced lymphoedema believed more strongly in the negative consequences of lymphoedema, which, in turn, led to higher levels of distress.

Another key finding is that greater beliefs in the ability to self-regulate negative affect predicted lower levels of distress. Research in both healthy individuals and clinical populations with Parkinson's disease and major depressive disorder suggests that the way in which affect is consciously controlled can change the way in which an individual processes and responds to stimuli (Beauregard, 2007). Thus, an inability to self-regulate negative affect may underlie the development of psychological distress (Beauregard, Paquette, & Lévesque, 2006; Gross & Miao, 1995). Although no other known study has investigated the relationship between self-regulation of affect and distress in the context of lymphoedema, breast cancer or chronic disease, self-regulation of affect has been associated with adherence to lymphoedema risk-management strategies in breast cancer survivors (Sherman & Koelmeyer, 2013; Sherman et al.,

2015). These findings suggest that the self-regulation of affect is an important coping-related factor underlying distress and health behaviour. Future research should investigate whether or not beliefs about the self-regulation of affect can be modified in order to lower distress or prevent the development of distress in women with breast cancer-related lymphoedema.

In the mediation analyses, beliefs in the negative consequences of lymphoedema and body image disturbance were identified as mediators of the relationship between women's stage of lymphoedema and their levels of distress. Women with more advanced lymphoedema had stronger beliefs in the negative consequences of lymphoedema and subsequently higher levels of depression and anxiety. In addition, women with more advanced lymphoedema had higher levels of body image disturbance and subsequently higher levels of depression, anxiety and stress. That these cognitive and affective factors were identified as significant mediators is consistent with the C-SHIP model (Miller et al., 1996) that informed the theoretical framework of this research. Targeted interventions to change these mediators may help minimise distress, particularly for women with more advanced symptoms of lymphoedema.

It is important to note that the moderating effect of age on the relationship between body image disturbance and distress found in a previous study (Alcorso & Sherman, 2015) was not repeated in these longitudinal analyses. In contrast to findings from the breast cancer literature, which found that younger women experienced greater distress associated with changes to their body due to breast cancer treatment (Przezdziecki et al., 2013), there were no differences found for younger versus older women and body image disturbance and distress over time.

There are some limitations to keep in mind when interpreting the results of this study. First, these data were obtained from self-report only, however, the use of an

online survey allowed for a good sample size. Future studies could improve upon this approach by obtaining reports from a partner, family member or friend on participants' level of distress, body image disturbance and illness representations develop a more in-depth understanding of how these variables interact to influence women's coping and distress. Second, the sample of women with breast cancer-related lymphoedema was heterogeneous in terms of medical characteristics. The women varied considerably in length of time since diagnosis, ranging from one year to over ten years of living with lymphoedema, as well as in the severity of their lymphoedema, with the majority reporting subclinical or mild lymphoedema. Finally, it is important to note that this study's sample was predominantly recruited from members of a consumer-based breast cancer organisation that explicitly expressed interest in participating in breast cancer-related research. Consequently, this sample of women with breast cancer-related lymphoedema are likely to be highly motivated to participate in research and highly experienced with completing online surveys.

In conclusion, the results of this study have implication for theory, practice and future research. The key findings of this study provide support for the CSM and C-SHIP social cognitive models of health behaviour, which predict that cognitive and affective illness representations, such as beliefs about the consequences and controllability of an illness, as well as self-regulation are associated with emotional outcomes. Health professionals need to be aware that women with breast cancer-related lymphoedema are at risk of experiencing psychological distress and they should aim to refer women to any available psychosocial support services and resources. Future research should aim to investigate potentially viable intervention strategies to reduce distress women with breast cancer-related lymphoedema. One promising is a web-based self-compassion based writing activity that aims to minimise distress related to the negative impact of

breast cancer-related lymphoedema on body image (Przezdziecki, Alcorso, & Sherman, 2015). Prior research has found that self-compassion mediates the relationship between body image disturbance and distress (Przezdziecki et al., 2013), and so by undertaking a structured writing exercise to increase self-compassion, this intervention may reduce the distress that arises due to the changes in a woman's body due to lymphoedema (e.g., swelling that requires wearing a visible compression garment and limits clothing choice).



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### **5.3 My Changed Body: Background, development and acceptability of a self-compassion based writing activity for female survivors of breast cancer**

This section includes a peer-reviewed journal article published in *Patient Education and Counseling*. The results of the longitudinal study on psychological distress (sections 5.1 and 5.2 in this chapter) highlight the association between body image disturbance and distress in women with breast-cancer related lymphoedema. An online intervention was developed to reduce distress in this population by increasing self-compassion via a structured writing activity. The intervention was the result of a collaboration between co-authors. The writing activity is intended to be adapted for both breast cancer survivors without lymphoedema and breast cancer survivors affected by lymphoedema. This manuscript describes the development and user acceptability of this intervention.

Przezdziecki, A., Alcorso, J. & Sherman, K.A. (2016). My changed body: Background, development and acceptability of a self-compassion based writing activity for female survivors of breast cancer. *Patient Education and Counseling*. doi: 10.1016/j.pec.2015.12.011





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Short communication

## My Changed Body: Background, development and acceptability of a self-compassion based writing activity for female survivors of breast cancer

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### ABSTRACT

**Objective:** To assess consumer and health professional user acceptability of a web-based self-compassion writing activity to minimize psychological distress related to the negative impact of breast cancer on body image.

**Methods:** "My Changed Body" is a web-based writing activity that combines expressive writing with a self-compassionate approach that focuses on cancer-related adverse body image alterations. Breast cancer survivors ( $n = 15$ ) and health professionals ( $n = 20$ ) provided feedback via a survey regarding the appearance, organization and content of the website and writing activity.

**Results:** Both breast cancer survivors and health professionals rated the website highly in terms of design, layout and content. Participants commented positively on the website's clear wording, appealing design and ease of navigation. Suggestions for improving the website included simplifying the instructions for the writing activity and allowing participants' writing to be saved.

**Conclusion:** Results from both breast cancer survivors and health professionals suggest a moderate to high level of user acceptability and positive ratings for the overall impression of the website.

**Practice implications:** Self-compassion based writing interventions can be translated to a web-based self-administered activity for body image difficulties after breast cancer treatment in a format that is acceptable to consumers and health professionals.

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### 1. Introduction

Breast cancer treatment can bring negative body changes, poor adjustment and ongoing psychological distress [1,2]. Central to this is the reality of change and loss regarding certain aspects of a woman's appearance and function. In addition, some women develop lymphoedema as a consequence of their treatment, characterized by severe swelling of the affected area, resulting in the need to wear visible compression garments [3], and consequently, further challenging the woman's body image [4–6]. The Cash theoretical model suggests that adverse appearance changes will increase the discrepancy between an individual's ideal and perceived body image, making her more likely to experience body image-related distress [7]. Unfortunately, body

image problems are not always adequately recognized or addressed, with evidence of unmet needs [1,2,7–9].

Many existing interventions designed to address body image difficulties after breast cancer treatment focus on couple or group formats within clinic settings [7], and have limited effectiveness for younger women [10]. Such approaches can be limited by demand for staff, cost, and the need to attend in-person, potentially resulting in poor accessibility [11]. There is a need for more interventions addressing body image distress that employ novel approaches, such as writing activities [7], that can be delivered in an individual, accessible format [12,13] which may especially benefit those with an increased reliance on online materials [14].

Expressive, unstructured writing has been used in the field of psychology [15] and oncology [16] to assist individuals who are experiencing distress. Writing interventions are a simple and inexpensive way to provide support, with evidence of physical and psychological benefits [15–17]. To date, unstructured writing has not been used to address cancer-related body image disturbances,

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Fig. 1. Screenshot of the My Changed Body website 'Welcome' page.

possibly as despite its many strengths, limited effectiveness in addressing body image concerns has been demonstrated by unstructured expressive writing in a variety of contexts [18–22]. Alternatively, self-compassion based approaches may be uniquely placed to address the difficulties associated with body image disturbance [23]. Thus, a need to investigate this possibility in the cancer context is indicated.

Self-compassion is a promising approach to assist with difficult life experiences, and has been linked to lower psychopathology [24]. It relates to a woman's ability to approach herself with kindness, a sense of mindful awareness about her circumstances, within a context of common humanity (i.e., knowing difficulties and loss are normal part of human life) [25]. A woman who is higher in self-compassion is likely to display less self-criticism, a more accurate appraisal of her losses, as well as the ability to place her problems within the broader context of life [25,26]. Furthermore, there is evidence that self-compassion is associated with decreased body image disturbance and psychological distress in breast cancer survivors [2], therefore making it a potentially valuable aspect to address.

In sum, combining unstructured writing with self-compassion-based prompts may provide dual benefits of decreasing distress and body image disturbance related to breast cancer treatment and its outcomes in a single intervention.

## 2. Methods

### 2.1. My Changed Body intervention development

#### 2.1.1. Website and content development

My Changed Body is a web-based writing intervention designed to address body image concerns arising from breast cancer and lymphedema. It entails a self-paced writing activity that is

estimated to take approximately 30 min to complete. The website provides "Welcome" page user instructions (Fig. 1) followed by information about the developers of the website. The remaining section comprises the intervention writing activity instructions, prompts and writing text boxes (Fig. 2). Six writing prompts are provided: (1) an introductory unstructured writing section where individuals write about a negative body image experience according to a modified Pennebaker [15] writing prompt; (2) treatment of one's body with kindness; (3) kind advice to oneself; (4) connection with others who experience difficulties with body image; (5) awareness of one's circumstances and reactions in a broader context; and, (6) a self-compassionate letter to the writer that acts as a summary of the most salient points of self-compassion as applied to one's own situation. Thus, the intervention user addresses self-kindness, common humanity and mindful awareness, as outlined by self-compassion research [25].

#### 2.1.2. Consultation with consumers and health care professionals and assessment of user acceptability

Following website development, consumers (breast cancer survivors) and health professionals experienced in breast cancer were given access to the website and provided feedback via an online survey regarding their perceptions of the website. Consumers and health professionals were recruited to ensure that we gathered perspectives from the population of women who would be using the intervention, as well as from health professionals who would be referring women to the intervention. Health professionals were recruited from the researchers' networks via an online advertisement. Consumers were recruited via the consumer-based breast cancer organization, the Breast Cancer Network Australia.

Participants were sent a link to the study website and asked to interact with all web pages before completing the online user

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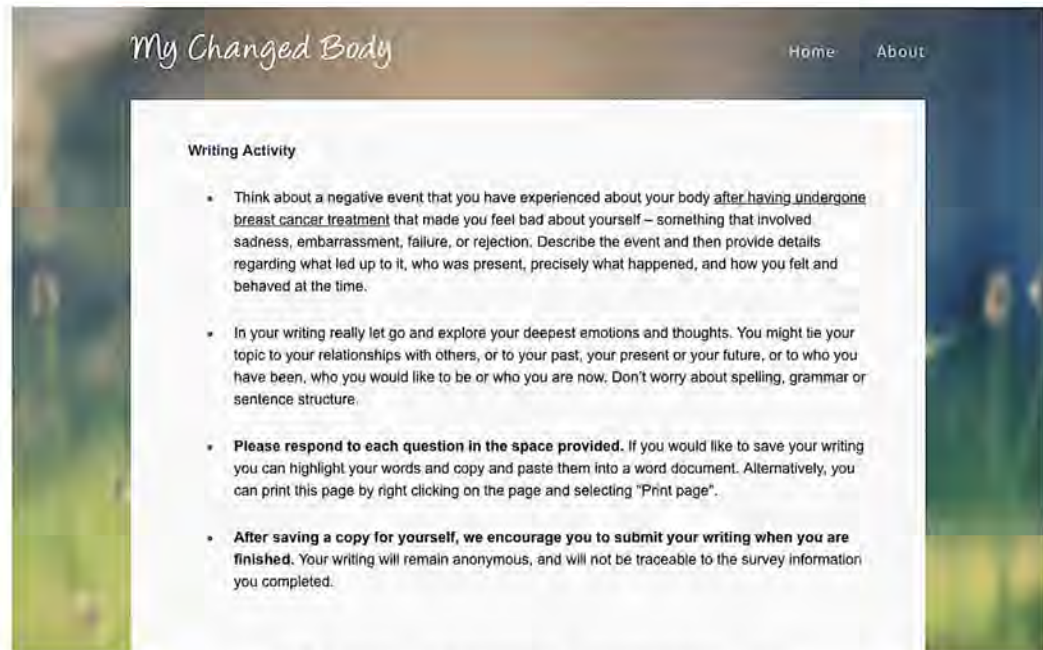


Fig. 2. Screenshot of the My Changed Body website writing activity page.

acceptability survey (both activities were estimated to take 20 min to complete). Feedback was provided for 18 statements regarding the overall impression of the website (e.g., "The website appeals to me"), website layout and design (e.g., "The website is easy to navigate") and website information and content (e.g., "The information contained in the website is clear") on a 5-point Likert-type scale (1 "strongly disagree" to 5 "strongly agree"). Demographic information and self-rated experience with websites was also collected, as well as providing free text sections for qualitative comments. In addition, the health professional survey collected the area of professional expertise, while the consumer survey collected information on the participants' breast cancer diagnosis, treatment and diagnosis of lymphedema.

### 3. Results

A total of 20 consumers and 15 health professionals participated in this study. Participant characteristics are displayed in Table 1. The mean rating for the overall impression of the website (5 items;  $\alpha = 0.81$ ) was 3.97 (SD = 0.78) for consumers and 3.96 (SD = 0.69) for health professionals. The mean rating for the website layout and design (7 items;  $\alpha = 0.95$ ) was 4.05 (SD = 0.69) for consumers and 3.98 (SD = 0.57) for health professionals. The mean rating for the website information and content (6 items;  $\alpha = 0.89$ ) was 3.96 (SD = 0.81) for consumers and 3.86 (SD = 0.56) for health professionals. A series of *t*-tests indicated that there were no significant differences between consumers' and health professionals' ratings of the website user acceptability ( $p = 0.100$ – $0.900$ ).

Thematic analysis was used to analyze the qualitative feedback provided by participants (Table 2). To achieve inter-rater agreement two researchers first independently coded participants' responses, and then together discussed and refined identified themes.

Table 1  
Participant characteristics.

Consumers (n = 20)	M (SD) or %
Age	58.22 (9.01)
Breast cancer diagnosis	
Early breast cancer	65%
Secondary breast cancer	0%
Ductal carcinoma in situ (DCIS)	30%
Lobular carcinoma in situ (LCIS)	5%
Breast cancer treatment	
Surgery	96%
Chemotherapy	57%
Radiation therapy	78%
Hormonal treatments	91%
Breast reconstruction surgery	30%
Lymphoedema diagnosis	22%
Level of experience using online activities provided through a website	
None or very low level of experience	0%
Low level of experience	9%
Neutral – neither high nor low level of experience	65%
High level of experience	26%
Very high level of experience	0%
Health Professionals (n = 15)	
Age	47.07 (8.63)
Number of years working in oncology	12.93 (8.06)
Occupation	
Nursing	27%
Physiotherapy	20%
Occupational therapy	20%
Psychology	7%
Other	26%
Level of experience using online activities provided through a website	
None or very low level of experience	7%
Low level of experience	0%
Neutral – Neither high nor low level of experience	33%
High level of experience	53%
Very high level of experience	7%

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**Table 2**  
User acceptability themes and supporting quotations from thematic analysis of qualitative feedback.

Theme	Supporting quotations from health professionals (HP) and consumers (C)	Response to feedback
Comments on what participants liked about the website.		
Clear wording	HP The text was clear. C Straightforward explanations.	No changes.
Appealing design	HP I really liked the color scheme and design – felt really warm and inviting. C Appealing, user friendly and a useful platform to express ideas, thoughts, emotions encountered on the BC journey.	No changes.
Easy to navigate	HP The website is easy to navigate and not too cluttered or busy looking. C I liked that the website was simple and easy to navigate.	No changes.
Participants' suggestions for improvements to the website.		
Allow writing to be saved.	HP: It would be so great if after the women completed the sections of the writing task, 'print' button would be available, so they can print/save their answers for later use. C: Also I was confused by the message that the text written wouldn't be saved . . . However, it does seem somewhat pointless for people to write/type/spend time on that for the words not to be considered important.	Option provided to participants to print their writing and/or save it to their desktop computer.
Simplify the instructions	HP: I found the instructions somewhat wordy and confusing. C: The instructions are a bit wordy.	Instructions simplified and bullet points were used to break up the text to make it easier to read.
Negative focus	HP: I found it confronting being asked to write about negative experiences upfront for both the non-lymphedema and lymphedema clients. C: I found the early and repeated emphasis on negative feelings really off putting.	Invitations to participate in the pilot evaluation study will specify that the writing intervention includes discussing "negative events" to ensure that women have accurate expectations of what participation will involve.

## 4. Discussion and conclusion

### 4.1. Discussion

My Changed Body is a theoretically-based [7,15,16] web-based writing intervention developed to assist breast cancer survivors with body image disturbance resulting from cancer treatment. Results from both breast cancer survivors and health professionals suggest a moderate to high level of user acceptability and positive ratings. Participants reported favorably on the website's clear wording, appealing design and ease of navigation. Suggestions were made by study participants for improving the website, including simplifying the instructions and allowing participants to save or print their writing.

### 4.2. Limitations

These findings provide preliminary support for the use of this body image-focused intervention. However, a few limitations should be noted. Two participants expressed concerns about the principally negative focus of the writing activity. It is possible that they were expecting positively-focused cognitive-behavioral self-esteem enhancing activities [7]. To ensure that participants have accurate expectations of the My Changed Body intervention, information about the activity has been revised to include the discussion of negative events and body image concerns. Body image disturbance, self-compassion and distress were not measured in this study, so it is not possible to determine if these factors influenced participants' feedback. Finally, consumers were recruited from an online organization; therefore, women in this study may be more experienced with websites and more motivated to participate in research compared with the general breast cancer population.

### 4.3. Conclusion

Results suggest a moderate to high level of user acceptability for the overall impression of the website as well as layout, design and

content. A randomized controlled evaluation study is now underway to assess the impact of the intervention on self-compassion and body image disturbance in breast cancer survivors.

### 4.4. Practice implications

Self-compassion based writing interventions can be translated to a web-based, self administered activity for body image difficulties after breast cancer treatment in a format that is acceptable to consumers. This approach may also be considered for other situations where psychological distress, particularly for body image, is problematic and a self-paced, non-therapist delivered intervention is indicated.

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### Conflict of interest statement

All authors declare no conflict of interest.

### Ethical approval

All procedures performed in studies involving human participants were in accordance with the ethical standards of the institution: Macquarie University Human Research Ethics Committee (Medical Sciences), Reference No. 5201401083, Title "Online Self-Compassion Activity for Body Image in Breast Cancer Survivors".

Informed consent: Informed consent was obtained from all individual participants included in the study.

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## **Chapter 6. Discussion**

This thesis addresses two gaps in our knowledge about breast cancer-related lymphoedema, the psychological factors preding: (1) adherence to self-management behaviours; and, (2) psychological distress in women living with breast cancer-related lymphoedema. This section will summarise the key findings from the empirical studies related to each aim, and integrate these findings into previous research and the overall theoretical framework of the thesis. In addition, the limitations of this thesis and implications for research and practice will be discussed.

### **Adherence**

Adherence to self-management behaviours (i.e., wearing a compression garment and following good hygiene and skin care) is a critical component of the overall treatment approach for breast cancer-related lymphoedema (ISL, 2013; Merchant & Chen, 2015; NLN, 2011; Ochalek, Gradalski, & Szygula, 2015). Despite this, previous research suggests that in women with breast cancer-related lymphoedema, adherence to self-management behaviours ranges from less than 30% (Tidhar & Katz-Leurer, 2010) to 69% (Brown, Cheville, Tchou, Harris, & Schmitz, 2014). Indeed, the research in this thesis found that only approximately one in five women are completely adherent to their self-management regimen (Alcorso, Sherman, Koelmeyer, Mackie, & Boyages, 2015). The research question addressed in the first part of this thesis is, “What cognitive and affective factors predict adherence to self-management behaviours in women with breast-cancer related lymphoedema?” To answer this question, a longitudinal study and cross-sectional study were conducted (Chapter 3). The design of these studies was informed by the Common Sense Model of illness representation (Diefenbach &

Leventhal, 1996) and the Cognitive-Social Health Information Processing (C-SHIP) model (Miller & Diefenbach, 1998), which predict that cognitive and affective illness representations (e.g., beliefs about the consequences of an illness, illness-related affect, self-efficacy and self-regulatory ability) are associated with health behaviours.

The aim of the longitudinal study was to determine whether cognitive and affective factors predict changes in adherence to self-management practices over time in women with breast cancer-related lymphoedema. Based on predictions from theory (Diefenbach & Leventhal, 1996; Miller & Diefenbach, 1998) and previous research in the at-risk (Sherman & Koelmeyer, 2013; Sherman, Miller, Roussi, & Taylor, 2015) population, it was hypothesised that knowledge, self-efficacy, beliefs about the controllability and consequences of lymphedema and lymphedema-related distress, and self-regulatory ability to manage lymphoedema-related distress would be predictors of adherence. To test this hypothesis, a longitudinal study was conducted using online surveys conducted at baseline, 6- and 12-months.

The results of the baseline data analysis (Chapter 3, Section 3.1) revealed that of the cognitive and affective factors, only knowledge was significantly correlated with total adherence (Alcorso et al., 2015). In the regression analyses, only medical history factors (time since diagnosis and receiving hormone replacement therapy) were associated with higher levels of total adherence (Alcorso et al., 2015). In the longitudinal analyses (Chapter 3, Section 3.2), cognitive and affective factors were examined in relation to individual self-management behaviours (i.e., adherence to exercise and self-lymphatic drainage) rather than to total adherence across all behaviours. This approach was taken for two reasons: (1) adherence to most behaviours, such as skin care and avoiding injury, were high and stable over time, and (2) many of the self-management behaviours were qualitatively different from each other, with some

requiring daily enactment (e.g., wearing a compression garment and performing exercises), while others required only general ongoing awareness (e.g., monitoring the affected area for changes and avoiding injury). Adherence to exercise and self-lymphatic drainage significantly decreased over time, but none of the cognitive and affective factors were found to be significant predictors of adherence to these self-management behaviours. However, a non-significant trend was evident for greater beliefs about self-efficacy being associated with adherence to exercise.

In sum, the study hypotheses were not supported: Cognitive and affective factors did not significantly predict adherence to self-management behaviours. Thus, the at-risk population may not be an informative comparison group for understanding adherence in women affected by breast cancer-related lymphoedema (Sherman & Koelmeyer, 2013; Sherman et al., 2015). Furthermore, these findings suggest that future studies examining self-care adherence should use an alternative theoretical framework, as predictions made from the CSM (Diefenbach & Leventhal, 1996) and C-SHIP model (Miller & Diefenbach, 1998) were not supported. It may be that cognitive and affective factors are more relevant for predicting individuals' responses to a health threat, such as breast cancer survivors' adherence to risk-management strategies when faced with the threat of developing lymphoedema, in comparison to predicting adherence to chronic disease self-management.

In order to gain further insight into what factors underlie adherence to self-management, a cross-sectional study was conducted to compare the perceptions of lymphoedema therapists with those of women affected with lymphoedema regarding barriers to self-management adherence (Chapter 3, Section 3.3). In qualitative studies, women reported a number of barriers to self-management, including financial cost (e.g., of compression garments) (James, 2011; Ridner, Dietrich, & Kidd, 2011), physical

limitations (James, 2011; Ridner et al., 2011), lack of time (Radina, Armer, & Stewart, 2014; Ridner et al., 2011), limited social support (James, 2011) and insufficient knowledge (Ridner et al., 2011). Based on previous research that compared patient and physician reported barriers to colorectal cancer screening, (Klabunde et al., 2005) the only known published study comparing patient and physicians on perceived barriers to adherence, we predicted that there would be significant differences between the extent to which affected women and therapists agreed that each barrier negatively impacted self-management adherence. In support of this hypothesis, there was a significant difference between groups on the extent to which they agreed that each barrier negatively influences adherence. Therapists were significantly more likely to agree that each potential barrier influenced adherence, whereas affected women were more likely to disagree.

Taken together, the findings from the empirical studies in this thesis suggest that, despite predictions from theory and previous research with the at-risk population, cognitive and affective factors may not be the key to understanding adherence to self-management in women with breast cancer-related lymphoedema. In addition, barriers identified through qualitative research, such as financial cost (James, 2011; Radina et al., 2014; Ridner et al., 2011), do not appear to be significantly affecting adherence for these women. Perhaps we should take a different perspective when designing future studies. Instead of looking for *barriers* to adherence, we could look at women who are successfully self-managing their lymphoedema to identify what factors *facilitate* adherence. One study found that self-compassion is associated with health-promoting behaviours (Sirois, Kitner, & Hirsch, 2014). It would be worthwhile to measure levels of self-compassion in women with breast cancer-related lymphoedema to determine if having the intrinsic

characteristics of being able to treat oneself with kindness, recognise that one is not alone in one's experience and being mindful of the challenges one faces living with lymphoedema (Neff, 2003) is associated with better self-management.

Another factor that might facilitate adherence is effective patient-provider communication. A gap in the lymphoedema literature is a lack of understanding about the extent to which patient-provider communication plays a role in adherence. The extent to which communications from different health professionals influence adherence was investigated in the at-risk population (Sherman & Koelmeyer, 2011), whereby nurse-led communications about lymphoedema risk were found to be the most effective at promoting adherence. Looking to other health conditions, physician communication has also been associated with patient adherence to diabetes self-management practices (Heisler, Bouknight, Hayward, Smith, & Kerr, 2002). Diabetes is a useful comparator for the lymphoedema context as the diabetes self-care regimen is similar to lymphoedema self care with good hygiene and skin care, exercise, and even compression garments use (for patients with leg ulcers), being common to both conditions (Cullum, Nelson, Fletcher, & Sheldon, 2001; Heisler et al., 2002; Partsch & Mortimer, 2015). Taken together, this suggests that patient-provider communication may be an important factor associated with adherence to lymphoedema self-management, a relationship that can be explored in future research.

Finally, future research can investigate potentially viable intervention strategies to improve adherence to self-management behaviours in women with breast cancer-related lymphoedema. Education will be an important component of any intervention, as knowledge about lymphoedema self-management was strongly associated with adherence in this research (Alcorso et al., 2015) and in the at-risk population (Sherman & Koelmeyer, 2011). Knowledge has also been associated with adherence in other

health conditions, such as asthma (Mancuso, Sayles, & Allegrante, 2010; Scherer & Bruce, 2001) and heart disease (Alm-Roijer, Stagmo, Udén, & Erhardt, 2004). Currently, a randomised controlled trial is underway to investigate the effectiveness of a web- and mobile-based intervention for lymphoedema self-care for breast cancer survivors that focuses on patient education (Fu et al., 2016). Symptoms, quality-of-life and adherence to self-care will be measured over a twelve week period. Importantly, personal contextual factors, similar to those included in the CSM (e.g., perceived effectiveness of the exercises demonstrated in the intervention), will be measured, and are hypothesised to be important factors underlying responses to the intervention.

In addition, a recent study (Ridner et al., 2014). suggests that encouraging women to self-monitor their lymphoedema symptoms may improve adherence to self-management behaviours. In this study, women who self-monitored their arms using Bioelectric Impedance Spectroscopy (BIS) had higher levels of adherence to compression garment use in comparison to a control group that did not self-monitor. Importantly, compression garment use remained higher in the intervention group even after the self-monitoring period ended. Future research should investigate self-monitoring as an intervention to improve adherence in breast cancer-related lymphoedema.

## **Distress**

Lymphoedema is associated with psychological distress (i.e., depression, anxiety and stress; Fu et al., 2013); women who develop breast cancer-related lymphoedema often experience greater psychological distress compared with breast cancer survivors unaffected by lymphoedema (Chachaj et al., 2010; Dominick, Natarajan, Pierce, Madanat, & Madlensky, 2014; Khan, Amatya, Pallant, & Rajapaksa, 2012; Pyszel,

Malyszczak, Pyszel, Andrzejak, & Szuba, 2006). Specifically, lymphoedema has been associated with negative changes in self-identity, including body image disturbance (Fu et al., 2013; Jäger, Döller, & Roth, 2006; Rhoten, Radina, Adair, Sinclair, & Ridner, 2015; Teo, Novy, Chang, Cox, & Fingeret, 2015) and perceived disability (Fu & Rosedale, 2009; Fu, 2008; Fu et al., 2013). From a social perspective, lymphoedema can lead to social isolation (Bogan, Powell, & Dudgeon, 2007; Fu & Rosedale, 2009; Towers, Carnevale, & Baker, 2008) and diminished sexuality and sexual functioning (Radina, Fu, Horstman, & Kang, 2015; Winch et al., 2015), as well as feelings of marginalisation in the health system (Ridner, Bonner, Deng, & Sinclair, 2012). Furthermore, the challenges of living with lymphoedema can elicit negative affect (i.e., unpleasant emotions such as fear, worry, anger and sadness) (Fu & Rosedale, 2009; Fu, 2008; Greenslade & House, 2006).

Despite numerous studies on the prevalence and characteristics of distress in women with breast cancer-related lymphoedema, there is limited research on the specific factors associated with distress. Thus, the second aim of this thesis was to identify psychosocial predictors of psychological distress (depression, anxiety and stress) in women with breast cancer-related lymphoedema. The empirical research conducted to address this aim was informed by the CSM, which predicts that cognitive and affective illness representations are associated with physical and emotional patient outcomes (Leventhal, Leventhal, & Contrada, 1998). In support of this theory, 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 psychological distress across multiple illness types (Hagger & Orbell, 2003), including breast cancer (Fischer et al., 2013; McCorry et al., 2013). Along with cognitive and affective illness representations, body image disturbance was included as a key factor in

the research in this thesis based on previous research with women with breast cancer-related lymphoedema. In several qualitative studies (Fu & Rosedale, 2009; Heppner et al., 2009; Ridner et al., 2012) women with breast cancer-related lymphoedema have reported body image difficulties as a source of distress. Furthermore, findings from a recent quantitative study (Teo et al., 2015) suggest that body image disturbance mediates the relationship between pain and depression. Thus, based on predictions from theory (Leventhal et al., 1998) and previous research (Fischer et al., 2013; Hagger & Orbell, 2003; McCorry et al., 2013; Teo et al., 2015), it was hypothesised that greater body image disturbance, greater beliefs in the negative consequences of lymphoedema and lower beliefs in the controllability of lymphoedema, treatment effectiveness and the ability to self-regulate negative affect would predict distress. The longitudinal study conducted in this thesis was designed to test this hypothesis, measuring distress and cognitive and affective factors at baseline, 6- and 12-months.

The baseline data from the longitudinal study were analysed to identify factors associated with distress in women with breast cancer-related lymphoedema (Chapter 5, Section 5.1). The results showed that 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 significantly associated with depression, anxiety and stress. Moreover, multivariate regression analyses indicated that body image disturbance remained significantly associated with depression, anxiety and stress, as did perceived treatment effectiveness, which was associated with stress. Furthermore, age was found to significantly moderate the relationship between body image disturbance and depression and anxiety, with older women experiencing greater body image disturbance more distressed. In the longitudinal analyses (Chapter 5, Section 5.2), beliefs about the



negative consequences of lymphoedema, beliefs about the ability to self-regulate negative affect and body image disturbance were significant predictors of depression, anxiety and stress. Furthermore, beliefs about the personal controllability of lymphoedema were significant predictors of anxiety.

In sum, the hypotheses were largely supported: greater body image disturbance, greater beliefs in the negative consequences of lymphoedema and lower beliefs in the controllability of lymphoedema and the ability to self-regulate negative affect were significant predictors of distress. Moreover, beliefs about lymphoedema treatment effectiveness were associated with distress. These findings are consistent with previous research in the lymphoedema context (Teo et al., 2015) as well as more broadly in oncology populations (Millar, Purushotham, McLatchie, George, & Murray, 2005; Sharpe, Patel, & Clarke, 2011). That illness representations are associated with distress is also consistent with theory. Both the CSM (Leventhal et al., 1998) and C-SHIP model (Miller & Diefenbach, 1998) predict that cognitive and affective factors, including beliefs about illness and self-regulation, influence individuals' subjective responses to illness.

The results of the longitudinal study on psychological distress highlight the association between body image disturbance and distress in women with breast-cancer related lymphoedema. An online intervention was developed to reduce distress in this population by increasing self-compassion via a structured writing activity. This intervention is based on previous research that suggests that self-compassion may act as a buffer against experiencing body image disturbance and distress in breast cancer survivors (Przedziecki et al., 2013). Furthermore, an online writing activity successfully induced self-compassion in a sample of participants from the general healthy population (Shapira & Mongrain, 2010) and expressive writing has been used to

process traumatic events and negative experiences (Pennebaker & Beall, 1986), with long-term benefits for emotional health, especially for individuals with severe levels of distress (Baikie & Wilhelm, 2005). The intervention in this thesis involved asking women to write in response to a series of writing prompts based on the components of self-compassion, including self-kindness, common humanity, and mindfulness (Neff, 2003).

After developing the website for the online writing activity, a study was undertaken to determine the user acceptability of the intervention. This involved asking consumers (breast cancer survivors) and health professionals with experience in breast cancer and breast cancer-related lymphoedema (e.g., nurses, psychologists, lymphoedema therapists) to rate their overall impression of the website as well as the website layout, design, information and content. The results of the user acceptability study suggest a moderate to high level of user acceptability of the intervention for breast cancer survivors, including women with breast cancer-related lymphoedema. A randomized controlled evaluation study is currently underway to assess the effectiveness of the intervention for increasing self-compassion and decreasing body image disturbance and distress in breast cancer survivors with lymphoedema. Furthermore, findings from this study suggest that self-compassion based writing interventions can be translated to a web-based, self administered activity for body image difficulties after breast cancer treatment in a format that is acceptable to consumers. Future research should continue to evaluate the effectiveness of self-compassion based interventions for reducing body image disturbance and distress in women with breast cancer-related lymphoedema.

## **Limitations**

There are several limitations to consider when interpreting the results of this thesis. The first set of limitations relates to the representativeness of the study samples. The research in this thesis was conducted entirely online, and although this allowed for the recruitment of a relatively large sample of participants Australia-wide, it also excluded women with breast cancer-related lymphoedema who do not have the requisite skills in using a computer. Furthermore, participants were recruited from a breast cancer-related organisation's register of women who have explicitly expressed interest in participating in breast cancer-related interest. As a result, these women may have a higher level of both enthusiasm for, and experience with, completing online surveys. Thus, the samples obtained for the research in this thesis may not be fully representative of the target population of Australian women with breast cancer-related lymphoedema. It is also important to note that the results of this research may not generalise beyond women with breast cancer-related lymphoedema to individuals living with lymphoedema due to other types of cancer treatment and/or individuals with primary lymphoedema.

The second set of limitations relate to the research design and measures used in the studies in this thesis. First, the data collected across each study were self-report only, with no objective measures obtained for medical characteristics (e.g., diagnosis, lymphoedema stage or adherence to self-management behaviours). Future research could improve upon this limitation by accessing participants' clinical records and/or including reports from participants' family members or friends. A second limitation relates to participant recruitment: No specific inclusion/exclusion criteria were used beyond being an adult, English-speaking woman diagnosed with breast cancer-related lymphoedema. This resulted in heterogeneous study samples in terms of medical characteristics. The women in these studies varied widely in terms of their length of

time since diagnosis and the severity or stage of their lymphoedema. Future studies may be more informative if they are designed to follow women prospectively post-breast cancer treatment, or post-lymphoedema diagnosis, to assess how adherence behaviour varies over time and how psychological distress develops and resolves. A final limitation of this thesis to consider is that some of the measures used in each study were purpose-built and have not been validated nor used in previous research. Specifically, the measures of adherence to self-management behaviours and perceived barriers to self-management were designed for the aims of this thesis as there are currently no known validated measures of adherence to lymphoedema self-management nor barriers to self-management. Future research should aim to validate measures used in other oncology or chronic disease populations for use with individuals with lymphoedema.

## **Conclusion**

The findings from this thesis have important implications for lymphoedema therapists and other health professionals treating women with breast cancer-related lymphoedema. In regards to adherence to self-management, lymphoedema therapists should be aware that medical characteristics are important for identifying women at risk of nonadherence. Furthermore, it may be beneficial to assess patient knowledge of lymphoedema self-management, as increased knowledge is associated with higher levels of adherence. Levels of adherence to exercise and self-lymphatic drainage were found to decrease over time, and so lymphoedema therapists should monitor women to see if they are continuing to follow their prescribed self-management regimen. Finally, the mismatch between therapists' and affected women's beliefs about barriers to self-management suggests a need for improvements in communication between the client and health professional. It may be beneficial for therapists to discuss with each client

what her barriers to self-management are (if any), and to work with her to develop practical strategies to overcome these barriers. In regards to psychological distress, health professionals need to be aware that women with breast cancer-related lymphoedema are at risk of experiencing distress and body image disturbance. It may be beneficial to screen women for symptoms of depression, anxiety, stress and body image disturbance in order to identify who may benefit from additional psychosocial support. Self-compassion based writing interventions are a promising way to assist women who are distressed due to the negative impact of lymphoedema and breast cancer on their body. These interventions can be translated to a web-based, self-administered format that is accessible to health professionals and affected women.

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## **Appendices**

**Appendix A** – Longitudinal study questionnaires

**Appendix B** – Lymphoedema therapist study questionnaire

**Appendix C** – My Changed Body user acceptability study questionnaire

**Appendix D** – Ethical approval of studies

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## **Appendix A – Longitudinal Study**

### **Participant Information and Consent Form**

**Name of Project:** Lymphoedema: A common-sense approach to understanding predictors of psychological distress and patient adherence

**Purpose of the study:** You are invited to participate in a research study on the psychosocial impact of lymphoedema. The purpose of the study is to fill the existing knowledge gaps to better understand the experiences of patients with lymphoedema or individuals at risk of developing lymphoedema. The main objectives are to determine (1) what predicts psychological distress in lymphoedema patients and (2) what predicts adherence to lymphoedema management strategies, to inform (3) the development of viable intervention strategies to improve the health and well-being of lymphoedema patients. Primary and secondary lymphoedema patients as well as breast cancer patients who are at risk of developing lymphoedema as a result of cancer treatment will be included in the study.

**Who is conducting the study?** The study is being conducted by Jessica Alcorso to meet the requirements of a Doctor of Philosophy (PhD) under the supervision of A/Prof Kerry Sherman, Senior Lecturer in the Department of Psychology at Macquarie University. If you have any questions or concerns about the purpose of this research and/or what your participation would involve please contact A/Prof Kerry Sherman by phone (02 9850 6874) or e-mail ([kerry.sherman@mq.edu.au](mailto:kerry.sherman@mq.edu.au)).

**What will you be required to do?** If you decide to participate, you will be asked to complete a 20-minute online questionnaire three times - an initial questionnaire, and then two follow-up questionnaires, one in six months and another in one year. Upon completion of the six-month follow-up questionnaire you will receive a \$5 voucher for Gloria Jeans. You will receive another \$5 voucher upon completion of the 12 month follow-up questionnaire (\$10 total).

The questions will ask for information about your medical history, your beliefs and feelings about lymphoedema and your body, as well as your mood. If you experience any concerns about any lymphoedema symptoms please contact your treating physician to discuss these issues. Included in the questionnaire is a screening tool for symptoms of psychological distress. If you are concerned about symptoms of depression, anxiety and/or stress we encourage you to contact A/Prof Kerry Sherman by phone (02 9850 6874) or e-mail ([kerry.sherman@mq.edu.au](mailto:kerry.sherman@mq.edu.au)). If your scores on this screening tool indicate severe symptom levels of depression, anxiety and/or stress A/Prof Kerry Sherman will contact you to follow-up and refer you to a clinical psychologist for further support.

Any information or personal details gathered in the course of the study are confidential, except as required by law. The questionnaire is run by Qualtrics, a secure online program; however, there is a slight risk of a third party tracking responses. No individual will be identified in any publication of the results. Data will be password-protected and only the research investigators will have access to the data. A summary of the results of the data can be made available to you on request after the completion of the study. If you wish to receive a summary of the results please contact A/Prof Kerry Sherman.

Participation in this study is voluntary: you are not obliged to participate and if

you decide to participate, you are free to withdraw at any time without having to give a reason and without consequence.

The ethical aspects of this study have been approved by the Macquarie University Human Research Ethics Committee. If you have any complaints or reservations about any ethical aspect of your participation in this research, you may contact the Committee through the Director, Research Ethics (telephone (02) 9850 7854; email [ethics@mq.edu.au](mailto:ethics@mq.edu.au)). Any complaint you make will be treated in confidence and investigated, and you will be informed of the outcome.

By selecting "I agree to participate" you are indicating that you have read and understand the information and agree to participate in this research, knowing that you can withdraw from further participation in the research at any time without consequence. You can print a copy of this page for your records if you wish to do so. To start the questionnaire, please click "I agree to participate".

## **Baseline Questionnaire**

Please fill in the following information:

- ☐ Last name (surname):
- ☐ First name:
- ☐ Phone:
- ☐ E-mail:
- ☐ Please re-enter your e-mail:
- ☐ Date of birth (DD/MM/YYYY)

Do you identify as being an Australian Aboriginal, Indigenous or Torres Strait Islander?

- ☐ Yes
- ☐ No

What is the highest level of education that you have completed? (Please select one.)

- ☐ Less than Year 10
- ☐ School Certificate or equivalent
- ☐ High School Certificate
- ☐ Vocational/TAFE
- ☐ Some university
- ☐ Bachelor's degree
- ☐ Postgraduate degree

What is your household income?

- ☐ Less than \$50,000
- ☐ \$50,000 to \$99,000
- ☐ \$100,000 to \$150,000
- ☐ More than \$150,000
- ☐ I prefer not to say

What is your marital status?

- ☐ Single, never married
- ☐ Married or partnered
- ☐ Divorced or separated
- ☐ Widowed

What is your employment status?

- ☐ Full-time
- ☐ Part-time
- ☐ Retired
- ☐ Not employed

The following questions are about your medical history.

When were you diagnosed with lymphoedema? (MM/YYYY)

Based on the descriptions below, what stage of lymphoedema do you currently have?

**Stage 0 (sub-clinical/latent):** There are no visible changes to your arm, hand, or upper body at this point, but you may notice a difference in feeling, such as mild tingling, unusual tiredness, or slight heaviness. You can have stage 0 lymphoedema for months or years before obvious symptoms develop.

**Stage 1 (mild):** The arm, hand, trunk, breast, or other area appears mildly swollen. When you press the skin, a temporary small dent (or pit) forms. When you elevate the affected area of your body, the swelling is reduced; however, the swelling returns when you return to a normal position.

**Stage 2 (moderate):** The affected area is swollen and elevating it does not help. Pressing on the skin does not leave a pit or dent. Some changes to the skin have happened, such as inflammation, hardening, or thickening.

**Stage 3 (severe):** The affected area is very large and misshapen. The skin has become leathery, wrinkled, discoloured and/or lost elasticity.

- ☐ Stage 0 (Sub-clinical)
- ☐ Stage 1 (Mild)
- ☐ Stage 2 (Moderate)
- ☐ Stage 3 (Severe)
- ☐ I don't know.

Did you undergo lymph node surgery as part of your cancer treatment?

- ☐ Yes
- ☐ No
- ☐ I don't know

What type of lymph node surgery have you had?

- ☐ Sentinel node
- ☐ Axillary
- ☐ I don't know
- ☐ I did not have surgery

Did you undergo chemotherapy treatment for cancer?

- ☐ Yes
- ☐ No
- ☐ I don't know

Did you undergo radiation therapy for cancer?

- ☐ Yes
- ☐ No
- ☐ I don't know

Have you completed, or are you currently undergoing, hormone replacement therapy?

- ☐ Yes
- ☐ No
- ☐ I don't know

Please select if you have any of the following health conditions:

- ☐ Diabetes (Type 1)
- ☐ Diabetes (Type 2)
- ☐ Ischaemic heart disease (coronary heart disease)
- ☐ Stroke
- ☐ Asthma
- ☐ Chronic obstructive pulmonary disease (COPD)
- ☐ Chronic kidney disease
- ☐ None of the above

Do you have a chronic disease management plan (Enhanced Primary Care program or EPC) that entitles you to Medicare rebates for certain allied health services?

- ☐ Yes
- ☐ No
- ☐ I don't know

Do you have private health insurance that entitles you to claim some or all of the costs related to lymphoedema treatment? (e.g., compression garments, therapy, massage, antibiotics for cellulitis or infection)

- ☐ Yes
- ☐ No
- ☐ I don't know



Have you used a compression garment subsidy scheme?

NSW - EnableNSW

VIC - Lymphoedema Compression Garment Program (LCGP)

ACT - ACT Equipment Scheme (ACTES)

QLD - Compression garments for adults with malignancy-related lymphoedema

TAS - Community Equipment Scheme

WA - Community Aids and Equipment Program (CAEP)

NT - Lymphoedema Compression Garment Subsidy

National - Department of Veteran Affairs (DVA)

- ☐ Yes
- ☐ No
- ☐ I don't know

Please provide an estimate of your annual out-of-pocket costs for your lymphoedema treatment (e.g., compression garments, therapy, massage, antibiotics for cellulitis or infection):

- ☐ \$0 - \$500
- ☐ \$501 - \$1000
- ☐ \$1001 - \$1500
- ☐ \$1501 - \$2000
- ☐ \$2001 - \$2500
- ☐ More than \$2500
- ☐ I prefer not to say

Please select the type(s) of treatment you have undertaken for lymphoedema (if any):

- ☐ Bandaging
- ☐ Therapist-assisted manual lymphatic drainage
- ☐ Surgery – Lymph Node Transfer (LNT)
- ☐ Surgery – Liposuction
- ☐ Laser therapy

Please indicate if you experience any of the following symptoms in your limb(s) or area of your body affected by lymphoedema. If you have not experienced any symptoms, please select “I have not experienced any symptoms.”

- ☐ Heaviness
- ☐ Tingling/Pins and needles
- ☐ Stiffness
- ☐ Weakness
- ☐ Fatigue
- ☐ Swelling
- ☐ Skin feeling tight
- ☐ Pain
- ☐ Aching
- ☐ Discomfort
- ☐ Other (Please specify) \_\_\_\_\_
- ☐ I have not experienced any symptoms

Please indicate how frequently you perform the following behaviours on your limb(s) or area of your body affected by lymphoedema:

	Daily	2-3 Times a Week	Once a Week	2-3 Times a Month	Once a Month	Less than Once a Month	Never
Wear a compression garment or bandages.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Follow recommendations for safe exercise.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Practice good hygiene to keep skin and nails/toenails clean.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Actively avoid injury or infection to my affected arm or leg.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Perform simple (self) lymphatic drainage.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Elevate my affected arm or leg.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Monitor my affected limb for changes in colour, temperature or size.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Please select whether you believe the following statements are true or false.

	True	False
Graduated compression garments are tighter towards the upper arm to encourage the flow of lymph fluid out of the affected area.	<input type="radio"/>	<input type="radio"/>
Exercise is recommended to individuals with lymphoedema only to promote weight loss.	<input type="radio"/>	<input type="radio"/>
Proper skin care can improve the condition of the skin as well as help prevent or treat infection.	<input type="radio"/>	<input type="radio"/>
Individuals with lymphoedema should avoid using electric razors as a way to prevent injury and infection.	<input type="radio"/>	<input type="radio"/>
During self-lymphatic drainage (massage) the lymph fluid is massaged in the direction towards the lymph nodes that have been removed.	<input type="radio"/>	<input type="radio"/>
To reduce fluid in the affected area of your body, it helps to elevate the affected area.	<input type="radio"/>	<input type="radio"/>
There does not need to be an injury or entry site for infection to occur in the affected area of your body.	<input type="radio"/>	<input type="radio"/>

The following questions assess how you feel about your body and appearance.

	Not a lot	A little	Quite a bit	Very much
Have you been feeling self-conscious about your appearance?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Have you felt less physically attractive as a result of your lymphoedema?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Have you been dissatisfied with your appearance when dressed?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Have you been feeling less feminine or less masculine as a result of your lymphoedema?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Do you find it difficult to look at yourself naked?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Have you been feeling less sexually attractive as a result of your lymphoedema?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Did you avoid people because of the way you felt about your appearance?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Have you been feeling the treatment has left your body less whole?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Have you felt dissatisfied with your body?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Have you been dissatisfied with the appearance of the area of your body affected by lymphoedema?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

The following questions are about what you believe about lymphoedema and how you feel about your condition. Please select how much you agree or disagree with the following statements about lymphoedema.

	Strongly Disagree	Disagree	Neither Agree nor Disagree	Agree	Strongly Agree
My lymphoedema is a serious condition.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
My lymphoedema has major consequences on my life.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
My lymphoedema strongly affects the way others see me.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
My lymphoedema has serious financial consequences.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
My lymphoedema causes difficulties for those who are close to me.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Lymphoedema affects my relationships or causes difficulties for those who are close to me.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
There is a lot which I can do to control my lymphoedema.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
What I do can determine whether my lymphoedema gets better or worse.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
The course of my lymphoedema depends on me.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Nothing I do will affect my lymphoedema.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

	Strongly Disagree	Disagree	Neither Agree nor Disagree	Agree	Strongly Agree
I have the power to influence my lymphoedema.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
My actions will have no effect on the outcome of my lymphoedema.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

The following questions are about what you believe about lymphoedema and how you feel about your condition. Please select how much you agree or disagree with the following statements about lymphoedema.

	Strongly Disagree	Disagree	Neither Agree nor Disagree	Agree	Strongly Agree
There is very little that can be done to improve my lymphoedema.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
My treatment will be effective in improving my symptoms of lymphoedema.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
The negative effects of my lymphoedema can be prevented by my treatment.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
My treatment can control my lymphoedema.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
There is nothing which can help my lymphoedema.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
The symptoms of my lymphoedema are puzzling to me.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
My lymphoedema is a mystery to me.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I don't understand my lymphoedema.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
My lymphoedema doesn't make any sense to me.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I have a clear picture or understanding of my lymphoedema.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>



The following questions are about what you believe about lymphoedema and how you feel about your condition. Please select how much you agree or disagree with the following statements about lymphoedema.

	Strongly Disagree	Disagree	Neither Agree nor Disagree	Agree	Strongly Agree
I get depressed when I think about my lymphoedema.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
When I think about my lymphoedema I get upset.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
My lymphoedema makes me feel angry.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
My lymphoedema does not worry me.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Having lymphoedema makes me feel anxious.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
My lymphoedema makes me feel afraid.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I believe I have the ability to make the necessary lifestyle changes to carry out the recommended self-care practices to manage my lymphoedema.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I believe that I am able to calm myself down when anxious or worried about lymphoedema.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I believe I am able to limit the amount of stress experienced as a result of lymphoedema.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Please read each statement and circle a number 0, 1, 2 or 3 which indicates how much the statement applied to you over the past week. There are no right or wrong answers. Do not spend too much time on any statement.

The rating scale is as follows:

0 Did not apply to me at all

1 Applied to me to some degree, or some of the time

2 Applied to me to a considerable degree, or a good part of time

3 Applied to me very much, or most of the time

	0	1	2	3
I found it hard to wind down	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I was aware of dryness of my mouth	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I couldn't seem to experience any positive feeling at all	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I experienced breathing difficulty (eg, excessively rapid breathing, breathlessness in the absence of physical exertion)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I found it difficult to work up the initiative to do things	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I tended to over-react to situations	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I experienced trembling (eg, in the hands)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I felt that I was using a lot of nervous energy	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I was worried about situations in which I might panic and make a fool of myself	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I felt that I had nothing to look forward to	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I found myself getting agitated	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I found it difficult to relax	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I felt down-hearted and blue	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

	0	1	2	3
I was intolerant of anything that kept me from getting on with what I was doing	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I felt I was close to panic	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I was unable to become enthusiastic about anything	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I felt I wasn't worth much as a person	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I felt that I was rather touchy	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I was aware of the action of my heart in the absence of physical exertion (e.g, sense of heart rate increase, heart missing a beat)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I felt scared without any good reason	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I felt that life was meaningless	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Please select how frequently you have been advised to perform the following behaviours for the area of your body affected by lymphoedema:

	Daily	2-3 Times a Week	Once a Week	2-3 Times a Month	Once a Month	Less than Once a Month	Never
Wear a compression garment or bandages.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Follow recommendations for safe exercise.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Practice good hygiene to keep skin and nails/toenails clean.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Actively avoid injury or infection to my affected arm or leg.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Perform simple (self) lymphatic drainage.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Elevate my affected arm or leg.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Monitor my affected limb for changes in colour, temperature or size.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Thank you very much for completing this questionnaire. Your time is greatly appreciated.

### **Follow-up Questionnaire (six and twelve months)**

Please fill in the following information:

Last name (surname):

First name:

Phone:

E-mail:

Please re-enter your e-mail:

Please indicate if you experience any of the following symptoms in your limb(s) or area of your body affected by lymphoedema. If you have not experienced any symptoms, please select “I have not experienced any symptoms.”

- ☐ Heaviness
- ☐ Tingling/Pins and needles
- ☐ Stiffness
- ☐ Weakness
- ☐ Fatigue
- ☐ Swelling
- ☐ Skin feeling tight
- ☐ Pain
- ☐ Aching
- ☐ Discomfort
- ☐ Other (Please specify) \_\_\_\_\_
- ☐ I have not experienced any symptoms

Please indicate how frequently you perform the following behaviours on your limb(s) or area of your body affected by lymphoedema:

	Daily	2-3 Times a Week	Once a Week	2-3 Times a Month	Once a Month	Less than Once a Month	Never
Wear a compression garment or bandages.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Follow recommendations for safe exercise.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Practice good hygiene to keep skin and nails/toenails clean.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Actively avoid injury or infection to my affected arm or leg.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Perform simple (self) lymphatic drainage.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Elevate my affected arm or leg.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Monitor my affected limb for changes in colour, temperature or size.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Please select whether you believe the following statements are true or false.

	True	False
Graduated compression garments are tighter towards the upper arm to encourage the flow of lymph fluid out of the affected area.	<input type="radio"/>	<input type="radio"/>
Exercise is recommended to individuals with lymphoedema only to promote weight loss.	<input type="radio"/>	<input type="radio"/>
Proper skin care can improve the condition of the skin as well as help prevent or treat infection.	<input type="radio"/>	<input type="radio"/>
Individuals with lymphoedema should avoid using electric razors as a way to prevent injury and infection.	<input type="radio"/>	<input type="radio"/>
During self-lymphatic drainage (massage) the lymph fluid is massaged in the direction towards the lymph nodes that have been removed.	<input type="radio"/>	<input type="radio"/>
To reduce fluid in the affected area of your body, it helps to elevate the affected area.	<input type="radio"/>	<input type="radio"/>
There does not need to be an injury or entry site for infection to occur in the affected area of your body.	<input type="radio"/>	<input type="radio"/>

The following questions assess how you feel about your body and appearance.

	Not a lot	A little	Quite a bit	Very much
Have you been feeling self-conscious about your appearance?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Have you felt less physically attractive as a result of your lymphoedema?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Have you been dissatisfied with your appearance when dressed?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Have you been feeling less feminine or less masculine as a result of your lymphoedema?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Do you find it difficult to look at yourself naked?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Have you been feeling less sexually attractive as a result of your lymphoedema?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Did you avoid people because of the way you felt about your appearance?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Have you been feeling the treatment has left your body less whole?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Have you felt dissatisfied with your body?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Have you been dissatisfied with the appearance of the area of your body affected by lymphoedema?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>



The following questions are about what you believe about lymphoedema and how you feel about your condition. Please select how much you agree or disagree with the following statements about lymphoedema.

	Strongly Disagree	Disagree	Neither Agree nor Disagree	Agree	Strongly Agree
My lymphoedema is a serious condition.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
My lymphoedema has major consequences on my life.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
My lymphoedema strongly affects the way others see me.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
My lymphoedema has serious financial consequences.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
My lymphoedema causes difficulties for those who are close to me.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Lymphoedema affects my relationships or causes difficulties for those who are close to me.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
There is a lot which I can do to control my lymphoedema.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
What I do can determine whether my lymphoedema gets better or worse.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
The course of my lymphoedema depends on me.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Nothing I do will affect my lymphoedema.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

	Strongly Disagree	Disagree	Neither Agree nor Disagree	Agree	Strongly Agree
I have the power to influence my lymphoedema.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
My actions will have no effect on the outcome of my lymphoedema.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

The following questions are about what you believe about lymphoedema and how you feel about your condition. Please select how much you agree or disagree with the following statements about lymphoedema.

	Strongly Disagree	Disagree	Neither Agree nor Disagree	Agree	Strongly Agree
There is very little that can be done to improve my lymphoedema.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
My treatment will be effective in improving my symptoms of lymphoedema.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
The negative effects of my lymphoedema can be prevented by my treatment.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
My treatment can control my lymphoedema.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
There is nothing which can help my lymphoedema.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
The symptoms of my lymphoedema are puzzling to me.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
My lymphoedema is a mystery to me.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I don't understand my lymphoedema.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
My lymphoedema doesn't make any sense to me.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I have a clear picture or understanding of my lymphoedema.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

The following questions are about what you believe about lymphoedema and how you feel about your condition. Please select how much you agree or disagree with the following statements about lymphoedema.

	Strongly Disagree	Disagree	Neither Agree nor Disagree	Agree	Strongly Agree
I get depressed when I think about my lymphoedema.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
When I think about my lymphoedema I get upset.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
My lymphoedema makes me feel angry.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
My lymphoedema does not worry me.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Having lymphoedema makes me feel anxious.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
My lymphoedema makes me feel afraid.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I believe I have the ability to make the necessary lifestyle changes to carry out the recommended self-care practices to manage my lymphoedema.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I believe that I am able to calm myself down when anxious or worried about lymphoedema.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I believe I am able to limit the amount of stress experienced as a result of lymphoedema.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

To what extent do you agree or disagree with the following statements?

	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree
Concerns about my appearance and clothing choice influence whether or not I wear my compression garment.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Physical limitations or pain/discomfort prevent me from performing some or all of the self-care recommendations (e.g., wearing a compression garment or self-lymphatic massage).	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
The cost of compression garments prevents me from wearing them as often as my therapist recommended.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I don't have time to follow some or all of the self-care recommendations.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
A lack of social support prevents me from performing some or all of the self-care recommendations (e.g., help from partner, family or friends with self-care, transportation, child care, etc.).	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I have difficulty locating and/or traveling to a lymphoedema clinic or lymphoedema therapist for treatment.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I need more information in order to properly manage my lymphoedema.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Please read each statement and circle a number 0, 1, 2 or 3 which indicates how much the statement applied to you over the past week. There are no right or wrong answers. Do not spend too much time on any statement.

0 Did not apply to me at all

1 Applied to me to some degree, or some of the time

2 Applied to me to a considerable degree, or a good part of time

3 Applied to me very much, or most of the time

	0	1	2	3
I found it hard to wind down	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I was aware of dryness of my mouth	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I couldn't seem to experience any positive feeling at all	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I experienced breathing difficulty (eg, excessively rapid breathing, breathlessness in the absence of physical exertion)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I found it difficult to work up the initiative to do things	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I tended to over-react to situations	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I experienced trembling (eg, in the hands)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I felt that I was using a lot of nervous energy	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I was worried about situations in which I might panic and make a fool of myself	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I felt that I had nothing to look forward to	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I found myself getting agitated	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I found it difficult to relax	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I felt down-hearted and blue	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I was intolerant of anything that kept me from getting on with what I was doing	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I felt I was close to panic	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

	0	1	2	3
I was unable to become enthusiastic about anything	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I felt I wasn't worth much as a person	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I felt that I was rather touchy	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I was aware of the action of my heart in the absence of physical exertion (e.g, sense of heart rate increase, heart missing a beat)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I felt scared without any good reason	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I felt that life was meaningless	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Please select how frequently you have been *advised* to perform the following behaviours for the area of your body affected by lymphoedema:

	Daily	2-3 Times a Week	Once a Week	2-3 Times a Month	Once a Month	Less than Once a Month	Never
Wear a compression garment or bandages.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Follow recommendations for safe exercise.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Practice good hygiene to keep skin and nails/toenails clean.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Actively avoid injury or infection to my affected arm or leg.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Perform simple (self) lymphatic drainage.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Elevate my affected arm or leg.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Monitor my affected limb for changes in colour, temperature or size.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Thank you very much for completing this questionnaire. Your time is greatly appreciated.



## **Appendix B – Lymphoedema Therapists Study**

### **Participant Information and Consent Form**

**Name of Project:** A psychosocial approach to understanding lymphoedema self-management

**Purpose of the study:** You are invited to participate in a research study on the psychosocial impact of lymphoedema. The main objectives are to determine: (1) what predicts adherence to lymphoedema self-management, to inform (2) the development of viable intervention strategies to improve the health and well-being of women living with lymphoedema. This survey aims to capture the experiences of lymphoedema therapists, including physiotherapists, occupational therapists, massage therapists and registered nurses.

**Who is conducting the study?** The study is being conducted by Jessica Alcorso to meet the requirements of a Doctor of Philosophy (PhD) under the supervision of A/Prof Kerry Sherman, Associate Professor in the Department of Psychology at Macquarie University. If you have any questions or concerns about the purpose of this research and/or what your participation would involve please contact A/Prof Kerry Sherman by phone (02 9850 6874) or e-mail ([kerry.sherman@mq.edu.au](mailto:kerry.sherman@mq.edu.au)).

**What will you be required to do?** If you decide to participate, you will be asked to complete a 10-minute online survey. The questions will ask for information

about your experience treating women who are living with lymphoedema, including any self-management recommendations you provide. This survey is anonymous. The questionnaire is run by Qualtrics, a secure online program; however there is a slight risk of a third party tracking responses. No individual will be identified in any publication of the results. Data will be password-protected and only the research investigators will have access to the data. A summary of the results of the data can be made available to you on request after the completion of the study.

Participation in this study is entirely voluntary: you are not obliged to participate and if you decide to participate, you are free to withdraw at any time without having to give a reason and without consequence. The ethical aspects of this study have been approved by the Macquarie University Human Research Ethics Committee. If you have any complaints or reservations about any ethical aspect of your participation in this research, you may contact the Committee through the Director, Research Ethics (telephone (02) 9850 7854; email [ethics@mq.edu.au](mailto:ethics@mq.edu.au)). Any complaint you make will be treated in confidence and investigated, and you will be informed of the outcome.

By selecting "I agree to participate" you are indicating that you have read and understand the information and agree to participate in this research, knowing that you can withdraw from further participation in the research at any time without consequence. You can print a copy of this page for your records if you wish to do so. To start the questionnaire, please click "I agree to participate".

## **Questionnaire**

What is your occupation?

- ☐ Physiotherapist
- ☐ Massage Therapist
- ☐ Occupational Therapist
- ☐ Registered Nurse
- ☐ Other

For how many years have you been treating individuals living with lymphoedema?

Where is your practice located?

- ☐ ACT
- ☐ New South Wales
- ☐ Northern Territory
- ☐ Queensland
- ☐ South Australia
- ☐ Tasmania
- ☐ Victoria
- ☐ Western Australia

There may be a number of factors that influence adherence to lymphoedema self-management behaviours. Please consider the following statements and indicate how strongly you agree or disagree.

	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree
Concerns about appearance and clothing choice influence whether or not women wear their compression garments.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Physical limitations or pain/discomfort prevent women from performing some or all of the self-care recommendations (e.g., wearing a compression garment or self-lymphatic massage).	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
The cost of compression garments prevents women from wearing them as often as recommended.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Women do not have time to follow some or all of the self-care recommendations.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
A lack of social support prevents women from performing some or all of the self-care recommendations (e.g., help from partner, family or friends with self-care, transportation, child care, etc.).	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Women have difficulty locating and/or traveling to a lymphoedema clinic or lymphoedema therapist for treatment.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Women require more information in order	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree
to properly manage their lymphoedema.					
A lack of information, knowledge and/or understanding strongly influences adherence to lymphoedema self-management.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Motivation (or a lack thereof) strongly influences adherence to lymphoedema self-management.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Practical barriers strongly influence adherence to lymphoedema self-management.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Thank you very much for completing this questionnaire. Your time is greatly appreciated.



## **Appendix C – My Changed Body User Acceptability Study**

### **Participant Information and Consent Form**

**Name of Project:** My Changed Body

**Purpose of the study:** You are invited to give feedback on a study website that provides breast cancer survivors with a writing activity focused on feelings towards their body after developing lymphoedema. The purpose of this study is to assess user acceptability of a website developed as part of an online intervention for women with breast cancer-related lymphoedema.

**Who is conducting the study?** The study is being conducted by Jessica Alcorso to meet the requirements of a Doctor of Philosophy (PhD) under the supervision of A/Prof Kerry Sherman, Associate Professor in the Department of Psychology at Macquarie University. If you have any questions or concerns about the purpose of this research and/or what your participation would involve please contact A/Prof Kerry Sherman by phone (02 9850 6874) or e-mail ([kerry.sherman@mq.edu.au](mailto:kerry.sherman@mq.edu.au)).

**What does the study involve?** This study will require approximately 20 minutes of your time in total and will be conducted in two parts.

1) You will be asked to browse a website developed as an online intervention, which includes viewing all three webpages and navigating around the website. You will be asked to view a home page with instructions for an activity and then click a button to view the activity itself. You will be asked to read the instructions but not be required to

complete the activity. You will be encouraged to click the submission button and view the following information page. You will also be asked to view the "about" page which contains further information about the researchers conducting the study

2) After viewing all the website pages, we ask that you complete a short survey where you can provide ratings of the website and other feedback.

The ethical aspects of this study have been approved by the Macquarie University Human Research Ethics Committee. If you have any complaints or reservations about any ethical aspect of your participation in this research, you may contact the Committee through the Director, Research Ethics (telephone [02] 9850 7854, email: [ethics@mq.edu.au](mailto:ethics@mq.edu.au)). Any complaint you make will be treated in confidence and investigated, and you will be informed of the outcome.

Your decision to participate in this survey is completely voluntary; you are not obliged to participate and if you decide to participate, you are free to withdraw at any time without having to give a reason and without consequence. Also, if you feel uncomfortable about any of the questions you can choose not to answer those questions. Any information or personal details gathered in the course of this study are confidential. All results will be presented in a way that no person can be identified. Only researchers directly involved with the study will have access to the data. A summary of the results of the data can be made to you on request by contacting the primary investigator whose details are on the bottom of this page.

**What can I do if I would like to speak more about my feelings?** If you are a breast cancer survivor and would like to receive emotional support or further discuss your experiences of cancer treatment and lymphoedema, the NSW Cancer Council Helpline (phone number 131120) or Lifeline Counseling Services (phone number 13 11 14) can provide more help. These services are provided free of charge.



By filling out the question below, you are giving your consent to participate in this research. Please tick the box that states you have understood the nature of the study and wish to complete the on-line questionnaire.

I understand the nature of this research and have voluntarily agreed to participate in this study. I have read and understand the information above and any questions I have asked have been answered to my satisfaction. I agree to participate in this research knowing that I can withdraw from further participation in the research at any time without any consequence. I have printed a copy of the participant information sheet to keep.

Please tick the box below if you would like to take part in this study by viewing the website then completing the feedback questionnaire.

## Questionnaire – Consumers

Thank you for participating in this study. Please read the following directions:

**Step 1:** Please open a new browser window or tab and visit:

<http://www.mychangedbody.org>

You will view a home page with instructions for a writing activity and will be encouraged to click a button to view the activity. You will not be required to complete the activity, only view the webpages and navigate through the website for the purposes of providing feedback.

**Step 2:** After viewing all of the webpages, we ask that you come back to this page to complete a short survey providing feedback about the website. When you have finished browsing the website, please click next (>>) to continue.

Please indicate your gender

- ☐ Male
- ☐ Female

Please tell us your email address so that we can use this to be in touch with you during the study.

Please enter your email address again in the space below.

How old are you? Please enter your age in years

Please rate your experience in using online activities provided through a website

- ☐ No or very low levels of experience
- ☐ Low level of experience
- ☐ Neutral - neither low or high experience
- ☐ High level experience
- ☐ Very high level experience

Have you ever been diagnosed with breast cancer or DCIS? (please tick one)

- ☐ Yes
- ☐ No
- ☐ How long ago were you diagnosed with breast cancer or DCIS? Please write the number of MONTHS since your diagnosis below.

What category of breast cancer were you diagnosed with?

- ☐ Ductal Carcinoma in Situ (DCIS)
- ☐ Lobular Carcinoma in Situ (LCIS)
- ☐ Early breast cancer (breast cancer that has only affected the breast tissue, or both the breast tissue and lymph nodes under the arm)
- ☐ Secondary breast cancer (also known as advanced or metastatic breast cancer; occurs when the breast cancer cells spread to other, more distant parts of the body such as the bones, liver or lungs)
- ☐ I don't know

Did you receive surgery for breast cancer?

- ☐ Yes
- ☐ No

Did you receive chemotherapy for breast cancer?

- ☐ Yes
- ☐ No

Did you receive radiation treatment (radiotherapy) for breast cancer?

- ☐ Yes
- ☐ No

Did you receive hormonal treatments (e.g. Tamoxifen, Arimidex, Aromasin, Femara) for breast cancer?

- ☐ Yes
- ☐ No

Did you receive targeted therapy (e.g. Herceptin, Tykerb) for breast cancer?

- ☐ Yes
- ☐ No

Have you had reconstructive breast surgery after your treatment?

- ☐ Yes
- ☐ No

Have you been diagnosed with lymphoedema?

- ☐ Yes
- ☐ No

Please indicate the extent to which you agree with each of the following statements.

The website appeals to me

- ☐ Strongly Disagree
- ☐ Disagree
- ☐ Neither Agree nor Disagree
- ☐ Agree
- ☐ Strongly Agree

The home page is welcoming

- ☐ Strongly Disagree
- ☐ Disagree
- ☐ Neither Agree nor Disagree
- ☐ Agree
- ☐ Strongly Agree

I want to look at all sections of the website

- ☐ Strongly disagree
- ☐ Disagree
- ☐ Neither Agree nor Disagree
- ☐ Agree
- ☐ Strongly Agree

The topic of this website is interesting

- ☐ Strongly Disagree
- ☐ Disagree
- ☐ Neither Agree nor Disagree
- ☐ Agree
- ☐ Strongly Agree

It only took me a short time to feel comfortable with the website

- ☐ Strongly Disagree
- ☐ Disagree
- ☐ Neither Agree nor Disagree
- ☐ Agree
- ☐ Strongly Agree

The presentation is well organised

- ☐ Strongly Disagree
- ☐ Disagree
- ☐ Neither Agree nor Disagree
- ☐ Agree
- ☐ Strongly Agree

The website is easy to navigate

- ☐ Strongly Disagree
- ☐ Disagree
- ☐ Neither Agree nor Disagree
- ☐ Agree
- ☐ Strongly Agree

The colour scheme is appropriate

- ☐ Strongly Disagree
- ☐ Disagree
- ☐ Neither Agree nor Disagree
- ☐ Agree
- ☐ Strongly Agree

The colour scheme is appealing

- ☐ Strongly Disagree
- ☐ Disagree
- ☐ Neither Agree nor Disagree
- ☐ Agree
- ☐ Strongly Agree



The colour scheme helps the website to be clear and easy to read

- ☐ Strongly Disagree
- ☐ Disagree
- ☐ Neither Agree nor Disagree
- ☐ Agree
- ☐ Strongly Agree

I like the design of this website

- ☐ Strongly Disagree
- ☐ Disagree
- ☐ Neither Agree nor Disagree
- ☐ Agree
- ☐ Strongly Agree

The information contained in the website is clear

- ☐ Strongly Disagree
- ☐ Disagree
- ☐ Neither Agree nor Disagree
- ☐ Agree
- ☐ Strongly Agree

The instructions for the writing activity are easy to understand

- ☐ Strongly Disagree
- ☐ Disagree
- ☐ Neither Agree nor Disagree
- ☐ Agree
- ☐ Strongly Agree

When I look at the website, I know what to do next

- ☐ Strongly Disagree
- ☐ Disagree
- ☐ Neither Agree nor Disagree
- ☐ Agree
- ☐ Strongly Agree

The website feels complete

- ☐ Strongly Disagree
- ☐ Disagree
- ☐ Neither Agree nor Disagree
- ☐ Agree
- ☐ Strongly Agree

The information is useful

- ☐ Strongly Disagree
- ☐ Disagree
- ☐ Neither Agree nor Disagree
- ☐ Agree
- ☐ Strongly Agree

The content is user friendly

- ☐ Strongly Disagree
- ☐ Disagree
- ☐ Neither Agree nor Disagree
- ☐ Agree
- ☐ Strongly Agree

I would be happy to return to this website on another occasion

- ☐ Strongly Disagree
- ☐ Disagree
- ☐ Neither Agree nor Disagree
- ☐ Agree
- ☐ Strongly Agree

Please comment on what you liked about this website.

Please let us know what could be improved on this website.

Thank you for completing the questionnaire. Your feedback is greatly appreciated.

## **Questionnaire – Health Professionals**

Thank you for participating in this study. Please read the following directions:

**Step 1:** Please open a new browser window or tab and visit:

<http://www.mychangedbody.org>

You will view a home page with instructions for a writing activity and will be encouraged to click a button to view the activity. You will not be required to complete the activity, only view the webpages and navigate through the website for the purposes of providing feedback.

**Step 2:** After viewing all of the webpages, we ask that you come back to this page to complete a short survey providing feedback about the website. When you have finished browsing the website, please click next (>>) to continue.

Please indicate your gender

- ☐ Male
- ☐ Female

Please tell us your email address so that we can use this to be in touch with you during the study.

Please enter your email address again in the space below.

How old are you? Please enter your age in years

Please rate your experience in using online activities provided through a website

- ☐ No or very low levels of experience
- ☐ Low level of experience
- ☐ Neutral - neither low or high experience
- ☐ High level experience
- ☐ Very high level experience

Please indicate your specialty:

- ☐ Surgery
- ☐ Oncologist
- ☐ Nursing
- ☐ Physiotherapy
- ☐ Occupational therapy
- ☐ Social work
- ☐ Psychology
- ☐ Other

How many years have you been working in the field of oncology? Please write the number of years below:

Please indicate the extent to which you agree with each of the following statements.

The website appeals to me

- ☐ Strongly Disagree
- ☐ Disagree
- ☐ Neither Agree nor Disagree
- ☐ Agree
- ☐ Strongly Agree

The home page is welcoming

- ☐ Strongly Disagree
- ☐ Disagree
- ☐ Neither Agree nor Disagree
- ☐ Agree
- ☐ Strongly Agree

I want to look at all sections of the website

- ☐ Strongly disagree
- ☐ Disagree
- ☐ Neither Agree nor Disagree
- ☐ Agree
- ☐ Strongly Agree

The topic of this website is interesting

- ☐ Strongly Disagree
- ☐ Disagree
- ☐ Neither Agree nor Disagree
- ☐ Agree
- ☐ Strongly Agree

It only took me a short time to feel comfortable with the website

- ☐ Strongly Disagree
- ☐ Disagree
- ☐ Neither Agree nor Disagree
- ☐ Agree
- ☐ Strongly Agree

The presentation is well organised

- ☐ Strongly Disagree
- ☐ Disagree
- ☐ Neither Agree nor Disagree
- ☐ Agree
- ☐ Strongly Agree

The website is easy to navigate

- ☐ Strongly Disagree
- ☐ Disagree
- ☐ Neither Agree nor Disagree
- ☐ Agree
- ☐ Strongly Agree



The colour scheme is appropriate

- ☐ Strongly Disagree
- ☐ Disagree
- ☐ Neither Agree nor Disagree
- ☐ Agree
- ☐ Strongly Agree

The colour scheme is appealing

- ☐ Strongly Disagree
- ☐ Disagree
- ☐ Neither Agree nor Disagree
- ☐ Agree
- ☐ Strongly Agree

The colour scheme helps the website to be clear and easy to read

- ☐ Strongly Disagree
- ☐ Disagree
- ☐ Neither Agree nor Disagree
- ☐ Agree
- ☐ Strongly Agree

I like the design of this website

- ☐ Strongly Disagree
- ☐ Disagree
- ☐ Neither Agree nor Disagree
- ☐ Agree
- ☐ Strongly Agree

The information contained in the website is clear

- ☐ Strongly Disagree
- ☐ Disagree
- ☐ Neither Agree nor Disagree
- ☐ Agree
- ☐ Strongly Agree

The instructions for the writing activity are easy to understand

- ☐ Strongly Disagree
- ☐ Disagree
- ☐ Neither Agree nor Disagree
- ☐ Agree
- ☐ Strongly Agree

When I look at the website, I know what to do next

- ☐ Strongly Disagree
- ☐ Disagree
- ☐ Neither Agree nor Disagree
- ☐ Agree
- ☐ Strongly Agree

The website feels complete

- ☐ Strongly Disagree
- ☐ Disagree
- ☐ Neither Agree nor Disagree
- ☐ Agree
- ☐ Strongly Agree

The information is useful

- ☐ Strongly Disagree
- ☐ Disagree
- ☐ Neither Agree nor Disagree
- ☐ Agree
- ☐ Strongly Agree

The content is user friendly

- ☐ Strongly Disagree
- ☐ Disagree
- ☐ Neither Agree nor Disagree
- ☐ Agree
- ☐ Strongly Agree

I would be happy to return to this website on another occasion

- ☐ Strongly Disagree
- ☐ Disagree
- ☐ Neither Agree nor Disagree
- ☐ Agree
- ☐ Strongly Agree

Please comment on what you liked about this website.

Please let us know what could be improved on this website.

Thank you for completing the questionnaire. Your feedback is greatly appreciated.

## Appendix D – Ethical approval of studies



Office of the Deputy Vice-Chancellor (Research)

Research Office  
C5C Research HUB East, Level 3, Room 324  
MACQUARIE UNIVERSITY NSW 2109 AUSTRALIA

Phone +61 (0)2 9850 6848  
Fax +61 (0)2 9850 4465  
Email [ethics.secretariat@mq.edu.au](mailto:ethics.secretariat@mq.edu.au)

26 July 2013

Dr Kerry Sherman  
Department of Psychology  
Faculty of Human Sciences

Dear Dr Sherman

RE: "Lymphoedema: A common-sense approach to understanding predictors of psychological distress and patient adherence" (REF: 5201300366)

Thank you for your correspondence dated 11 July 2013 responding to the issues raised by the Macquarie University Human Research Ethics Committee (HREC (Medical Sciences)). The HREC (Medical Sciences) delegated the review of your responses to the Ethics Secretariat.

The HREC (Medical Sciences) is fully constituted and operates in accordance with the National Health and Medical Research Council's *National Statement on Ethical Conduct in Human Research* (2007) (the National Statement) and the *CPMP/ICH Note for Guidance on Good Clinical Practice*.

I am pleased to advise that the above project has been granted ethical and scientific approval.

This research meets the requirements of the National Statement which is available at the following website:

[http://www.nhmrc.gov.au/files\\_nhmrc/publications/attachments/e72.pdf](http://www.nhmrc.gov.au/files_nhmrc/publications/attachments/e72.pdf)

This letter constitutes ethical and scientific approval only.

The following documentation has been reviewed and approved by the HREC (Medical Sciences):

Documents reviewed	Version no.	Date
Macquarie University Ethics Application Form	1	Nov 2011
Response email and letter from co-investigator	N/A	5 June 2013
Macquarie University Amendment Request Form (undated)	N/A	N/A
Macquarie University Participant Information and Consent Form (PICF) - "Lymphoedema: A common-sense approach to understanding predictors of psychological distress and patient adherence" (v 2, dated 29 May 2013)	2	29 May 2013
Macquarie University PICF (Organisations), "Lymphoedema: A common-sense approach to understanding predictors of psychological distress and	1.0	7 May 2013

patient adherence"		
Advertisement, "Lymphoedema: A common-sense approach to understanding predictors of psychological distress and patient adherence"	N/A	N/A
Breast Cancer Patient Questionnaire (undated) incl:	N/A	N/A
a. Body Image Scale (BIS)		
b. Illness Perception Questionnaire Revised - IPQ-R		
c. Upper Limb Lymphoedema Scale - ULL-27		
d. Positive and Negative Affect Scale - PANAS		
e. Depression Anxiety Stress Scale - DASS		
Lymphoedema Patient Questionnaire (undated) incl:	N/A	N/A
a. Body Image Scale (BIS)		
b. Illness Perception Questionnaire Revised - IPQ-R		
c. Upper Limb Lymphoedema Scale - ULL-27		
d. Positive and Negative Affect Scale - PANAS		
e. Depression Anxiety Stress Scale - DASS		

Please note the following standard requirements of approval:

1. The approval of this project is conditional upon your continuing compliance with the National Statement. It is the responsibility of the Principal Investigator to ensure that the protocol complies with the HREC-approval and that a copy of this letter is forwarded to all project personnel.
2. The National Statement sets out that researchers have a "significant responsibility in monitoring, as they are in the best position to observe any adverse events or unexpected outcomes. They should report such events or outcomes promptly to the relevant institution/s and ethical review body/ies, and take prompt steps to deal with any unexpected risks" (5.5.3).

Please notify the Committee within 72 hours of any serious adverse events or Suspected Unexpected Serious Adverse Reactions or of any unforeseen events that affect the continued ethical acceptability of the project.

3. Approval will be for a period of five (5) years subject to the provision of annual reports.

NB. If you complete the work earlier than you had planned you must submit a Final Report as soon as the work is completed. If the project has been discontinued or not commenced for any reason, you are also required to submit a Final Report for the project.

Progress reports and Final Reports are available at the following website:

[http://www.research.mq.edu.au/for/researchers/how\\_to\\_obtain\\_ethics\\_approval/human\\_research\\_ethics/forms](http://www.research.mq.edu.au/for/researchers/how_to_obtain_ethics_approval/human_research_ethics/forms)

4. If the project has run for more than five (5) years you cannot renew approval for the project. You will need to complete and submit a Final Report and submit a new application for the project. (The five year limit on renewal of approvals allows the Committee to fully re-review research in an environment where legislation, guidelines and requirements are continually changing, for example, new child protection and privacy laws).

5. All amendments to the project must be reviewed and approved by the Committee before implementation. Please complete and submit a Request for Amendment Form available at the following website:

[http://www.research.mq.edu.au/for/researchers/how\\_to\\_obtain\\_ethics\\_approval/human\\_research\\_ethics/forms](http://www.research.mq.edu.au/for/researchers/how_to_obtain_ethics_approval/human_research_ethics/forms)

6. At all times you are responsible for the ethical conduct of your research in accordance with the guidelines established by the Hospital and University. This information is available at the following websites:

<http://www.mq.edu.au/policy/>

[http://www.research.mq.edu.au/for/researchers/how\\_to\\_obtain\\_ethics\\_approval/human\\_research\\_ethics/policy](http://www.research.mq.edu.au/for/researchers/how_to_obtain_ethics_approval/human_research_ethics/policy)

If you will be applying for or have applied for internal or external funding for the above project it is your responsibility to provide the Macquarie University's Research Grants Management Assistant with a copy of this email as soon as possible. Internal and External funding agencies will not be informed that you have ethics approval for your project and funds will not be released until the Research Grants Management Assistant has received a copy of this email.

If you need to provide a hard copy letter of ethics approval to an external organisation as evidence that you have approval please do not hesitate to contact the Ethics Secretariat at the address below.

Please retain a copy of this email as this is your official notification of ethics approval.

The HREC (Medical Sciences) wishes you every success in your research.

Yours sincerely

PP 

**Dr Karolyn White**

Director, Research Ethics

Chair, Human Research Ethics Committee (Medical Sciences)

cc. Ms Jessica Alcorso, Department of Psychology



31 July 2014

Associate Professor Kerry Sherman  
Department of Psychology  
Faculty of Human Sciences  
Macquarie University NSW 2109

Dear Associate Professor Sherman

RE: Lymphoedema: A common-sense approach to understanding predictors of psychological distress and patient adherence

Thank you for your correspondence dated 26 June 2014 submitting an amendment request to the above study. The Human Research Ethics Committee (HREC) (Medical Sciences) delegated review of these changes to the HREC (Medical Sciences) Executive.

I am pleased to advise that ethical approval of the following amendments to the above study has been granted:

1. Extension of the study to include health professionals treating patients with lymphoedema, including the recruitment of 50 lymphoedema therapists from the Australian Lymphoedema Association's public register for participation in an online survey.

This research meets the requirements set out in the *National Statement on Ethical Conduct in Human Research* (2007 – Updated March 2014) (the *National Statement*). This letter constitutes ethical and scientific approval only.

**Details of this approval are as follows:**

**Reference No:** 5201300366

**Approval Date:** 31 July 2014

The following documentation submitted with your email correspondence has been reviewed and approved by the HREC (Medical Sciences):

Documents reviewed	Version no.	Date
Macquarie University HREC Request for Amendment Form	2.0	Received 27/06/2014
Correspondence from Miss Jessica Alcorso addressing the HREC's feedback		Received 25/07/2014
Health Professional Participant Information & Consent Form and Questionnaire	1	16/06/2014
Research Invitation	1	16/06/2014



The HREC (Medical Sciences) Terms of Reference and Standard Operating Procedures are available from the Research Office website at:

[http://www.research.mq.edu.au/for/researchers/how\\_to\\_obtain\\_ethics\\_approval/human\\_research\\_ethics](http://www.research.mq.edu.au/for/researchers/how_to_obtain_ethics_approval/human_research_ethics)

Please do not hesitate to contact the Ethics Secretariat should you have any questions regarding your ethics application.

The HREC (Medical Sciences) wishes you every success in your research.

Yours sincerely



**Professor Tony Eyers**

Chair, Macquarie University Human Research Ethics Committee (Medical Sciences)

This HREC is constituted and operates in accordance with the National Health and Medical Research Council's (NHMRC) *National Statement on Ethical Conduct in Human Research* (2007) and the *CPMP/ICH Note for Guidance on Good Clinical Practice*.

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**MACQUARIE**  
**University**  
SYDNEY AUSTRALIA

5 February 2015

A/Prof Kerry Sherman  
Department of Psychology  
Faculty of Human Sciences  
MACQUARIE UNIVERSITY NSW 2109

Dear A/Prof Sherman

**Reference No:** 5201401083

**Title:** *"Online Self-Compassion Activity for Body Image in Breast Cancer Survivors"*

Thank you for submitting the above application for ethical and scientific review. Your application was considered by the Macquarie University Human Research Ethics Committee (HREC (Medical Sciences)) at its meeting on 27 November 2014 at which further information was requested to be reviewed by the Ethics Secretariat.

The requested information was received with correspondence on 20 January 2015.

I am pleased to advise that ethical and scientific approval has been granted for this project to be conducted at:

- Macquarie University

This research meets the requirements set out in the *National Statement on Ethical Conduct in Human Research* (2007 – Updated March 2014) (the *National Statement*).

This letter constitutes ethical and scientific approval only.

**Standard Conditions of Approval:**

1. Continuing compliance with the requirements of the *National Statement*, which is available at the following website:

<http://www.nhmrc.gov.au/book/national-statement-ethical-conduct-human-research>

2. This approval is valid for five (5) years, subject to the submission of annual reports. Please submit your reports on the anniversary of the approval for this protocol.

3. All adverse events, including events which might affect the continued ethical and scientific acceptability of the project, must be reported to the HREC within 72 hours.

4. Proposed changes to the protocol must be submitted to the Committee for approval before implementation.

It is the responsibility of the Chief investigator to retain a copy of all documentation related to this project and to forward a copy of this approval letter to all personnel listed on the project.

Should you have any queries regarding your project, please contact the Ethics Secretariat on 9850 4194 or by email [ethics.secretariat@mq.edu.au](mailto:ethics.secretariat@mq.edu.au)

The HREC (Medical Sciences) Terms of Reference and Standard Operating Procedures are available from the Research Office website at:

[http://www.research.mq.edu.au/for/researchers/how\\_to\\_obtain\\_ethics\\_approval/human\\_research\\_ethics](http://www.research.mq.edu.au/for/researchers/how_to_obtain_ethics_approval/human_research_ethics)

The HREC (Medical Sciences) wishes you every success in your research.

Yours sincerely



**Professor Tony Evers**

Chair, Macquarie University Human Research Ethics Committee (Medical Sciences)

This HREC is constituted and operates in accordance with the National Health and Medical Research Council's (NHMRC) *National Statement on Ethical Conduct in Human Research* (2007) and the *CPMP/ICH Note for Guidance on Good Clinical Practice*.

**Details of this approval are as follows:**

The following documentation submitted with your email correspondence has been reviewed and approved by the HREC (Medical Sciences):

Documents reviewed	Version no.	Date
Macquarie University HREC Request for Amendment Form	2.0	Received 16 April 2015
Part 2 – Stream A Consent & Questionnaire	4	14/04/2015
Part 2 – Stream B Consent & Questionnaire	4	14/04/2015
<i>“Conclusion: A letter to myself”</i> web-page screenshot		

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**MACQUARIE**  
University

4 May 2015

Associate Professor Kerry Sherman  
Department of Psychology  
Faculty of Human Science  
MACQUARIE UNIVERSITY NSW 2109

Dear A/Prof Sherman

**Reference No:** 5201401083

**Title:** *Online Self-Compassion Activity for Body- Image in Breast Cancer Survivors*

Thank you for your correspondence dated 16 April 2015 submitting an amendment request to the above study. Your proposed amendment was reviewed and approved by the Ethics Secretariat.

I am pleased to advise that ethical approval has been granted for the following amendments to the study:

- 1) Addition of an anonymous "submit" button and subsequent storage of responses by researchers

The HREC (Medical Sciences) Terms of Reference and Standard Operating Procedures are available from the Research Office website at:

[http://www.research.mq.edu.au/for/researchers/how\\_to\\_obtain\\_ethics\\_approval/human\\_research\\_ethics](http://www.research.mq.edu.au/for/researchers/how_to_obtain_ethics_approval/human_research_ethics)

Please do not hesitate to contact the Ethics Secretariat should you have any questions regarding your ethics application.

The HREC (Medical Sciences) wishes you every success in your research.

Yours sincerely

**Professor Tony Eyers**

Chair, Macquarie University Human Research Ethics Committee (Medical Sciences)

This HREC is constituted and operates in accordance with the National Health and Medical Research Council's (NHMRC) *National Statement on Ethical Conduct in Human Research* (2007) and the *CPMP/ICH Note for Guidance on Good Clinical Practice*.

**Details of this approval are as follows:**

The following documentation submitted with your email correspondence has been reviewed and approved by the HREC (Medical Sciences):

Documents reviewed	Version no.	Date
Macquarie University HREC Request for Amendment Form	2.0	Received 14/05/2015

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**MACQUARIE**  
University

29 May 2015

Associate Professor Kerry Sherman  
Department of Psychology  
Faculty of Human Sciences  
Macquarie University  
NSW 2109

Dear Associate Professor Sherman

**Reference No:** 5201401083

**Title:** *Online Self-Compassion Activity for Body Image in Breast Cancer Survivors*

Thank you for your correspondence dated 14 May 2015 submitting an amendment request to the above study. Your proposed amendment was reviewed and approved by the Ethics Secretariat.

I am pleased to advise that ethical approval has been granted for the following amendments to the study:

1. The expansion of recruitment to include Breast Cancer Care WA and private lymphoedema clinics in Sydney. The study invitation will be circulated to Lymphoedema therapists at Therapy for Life, Mt. Wilga Lymphoedema Clinic. The Macquarie University Hospital Physiotherapy Clinic therapists will circulate the study invitation via e-mail to clients who have expressed interest in participating in lymphoedema-related research.

The HREC (Medical Sciences) Terms of Reference and Standard Operating Procedures are available from the Research Office website at:

[http://www.research.mq.edu.au/for/researchers/how\\_to\\_obtain\\_ethics\\_approval/human\\_research\\_ethics](http://www.research.mq.edu.au/for/researchers/how_to_obtain_ethics_approval/human_research_ethics)

Please do not hesitate to contact the Ethics Secretariat should you have any questions regarding your ethics application.

The HREC (Medical Sciences) wishes you every success in your research.

Yours sincerely

**Professor Tony Evers**

Chair, Macquarie University Human Research Ethics Committee (Medical Sciences)

This HREC is constituted and operates in accordance with the National Health and Medical Research Council's (NHMRC) *National Statement on Ethical Conduct in Human Research* (2007) and the *CPMP/ICH Note for Guidance on Good Clinical Practice*.

**Details of this approval are as follows:**

The following documentation submitted with your email correspondence has been reviewed and approved by the HREC (Medical Sciences):

Documents reviewed	Version no.	Date
Macquarie University HREC Request for Amendment Form	2.0	Received 14/05/2015



## **Appendix E – Accepted oral conference presentations**

### **Sydney Postgraduate Psychology Conference.**

November 20, 2013. Sydney, Australia.



## Background

- **What is lymphoedema?** (NLN, 2011)

- Causes and incidence rates:

- Primary lymphoedema
- Secondary lymphoedema

- Illness progression



Source: ImpediMed

## Background

- **What is lymphoedema?**

- Physiological impact (NLN, 2011)

- Psychosocial impact (Fu et al., 2013)

- Treatment (NLN, 2011)

- Lymphoedema self-management recommendations (LSMRs) (Lasinsky, 2013)



## Literature Review

- **What do we know about patient adherence to LSMRs?**

- Patient adherence to LSMRs is critical for maintaining treatment outcomes and helping to prevent or slow the progression of the illness.

(Andersen, Højris, Erlandsen, & Andersen, 2000; Johnstone et al., 2006; Lasinski, 2013; Vignes et al., 2007)

- Adherence level <30% - 79% (Bani et al., 2007; Ridner, McMahon, Dietrich, & Hoy, 2008; Rose, Taylor, & Twycross, 1991; Tidhar & Katz-Leurer, 2010)

## Literature Review

- **What do we know about patient adherence to LSMRs?**

- Factors associated with adherence

- **Contextual factors**

- Medical history (Ridner et al., 2008)
- Physical functioning (Newman, Brennan, & Passik, 1996; Ridner, Dietrich, & Kidd, 2011)

- **Psychosocial factors**

- Illness representations (James, 2011; Ridner et al., 2011)
- Knowledge (Bani et al., 2007)
- Psychological functioning (Newman, Brennan, & Passik, 1996; Ridner et al., 2011)

## Theoretical framework and conceptual model

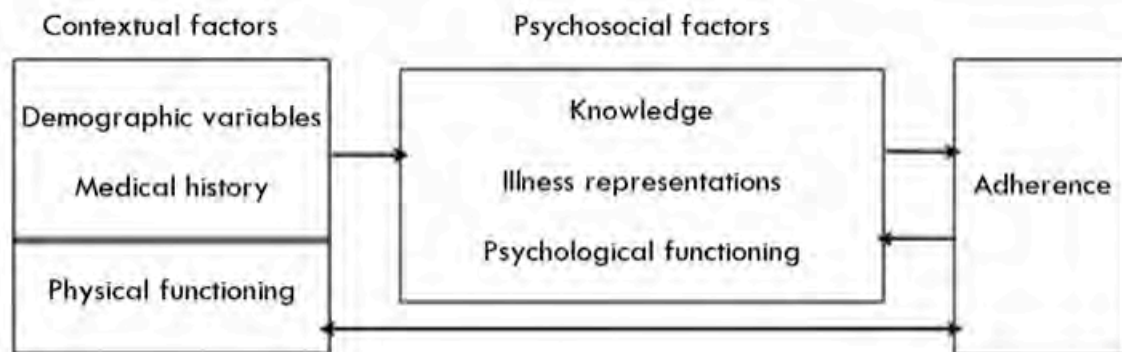


Figure 1. Conceptual model illustrating the key factors associated with adherence to lymphedema self-management strategies.

## Implications and directions for future research

- Refine conceptual model and improve understanding of the patient experience of lymphoedema
- Identify potentially viable intervention strategies



# Questions and Feedback

Thank you!

jessica.alcorso@mq.edu.au



## References

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**Australasian Society for Behavioural Health and Medicine (ASBHM)  
Conference.**

February 12-14, 2014. Auckland, New Zealand.

*Travel scholarship recipient.*

**A PSYCHOSOCIAL APPROACH TO UNDERSTANDING LYMPHOEDEMA  
SELF-MANAGEMENT**

Jessica Alcorso<sup>1</sup>, Kerry A. Sherman<sup>1,2</sup>

<sup>1</sup>Centre for Emotional Health, Department of Psychology, Macquarie University,  
Sydney, Australia

<sup>2</sup>Westmead Breast Cancer Institute, Sydney, Australia

Lymphoedema is a chronic condition arising from a malfunction of the lymphatic system that can be physically disabling due to symptoms including swelling, pain and functional impairment. Lymphoedema also impacts negatively on the affected individual from a psychological and social perspective with impaired quality of life, increased distress and diminished capacity to undertake paid employment. A critical component of the effective management of this condition is the self-management guidelines given to patients including avoiding trauma to the affected limb, skin care and wearing compression garments. Despite the importance of patient adherence to self-care guidelines little is known about actual levels of adherence or the factors underlying adherence to these recommendations. Emerging evidence suggests that a range of psychosocial factors may influence patient adherence to lymphoedema self-management guidelines. In order to understand why some individuals are adhering to their self-care guidelines when others are non-adherent, we need to consider a broad range of factors that may underlie the enactment of these behaviours. In particular, if

improving treatment outcomes and relieving symptoms for patients is a priority, it is important to identify which patients are at risk of being poorly adherent in order to intervene early to maximise patient wellbeing. We present an integrated conceptual framework for understanding patient adherence in the lymphoedema context, and to inform the design and direction of future research in this area. Such a framework provides guidance on the choice of research questions to investigate, with research findings, in turn, providing an iterative function allowing the model to be further refined.

## **A psychosocial approach to understanding lymphoedema self-management**

**Jessica Alcorso and A/Prof Kerry A. Sherman**

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## Understanding lymphoedema self-management

**What is lymphoedema?** (NLN, 2011)



Source: ImpediMed

## Understanding lymphoedema self-management

**What do we know about patient adherence to lymphoedema self-management recommendations?**

- Patient adherence is critical for maintaining treatment outcomes and helping to prevent or slow the progression of the illness. (Andersen, Højris, Erlandsen, & Andersen, 2000; Johnstone et al., 2006; Lasinski, 2013; Vignes et al., 2007)
- Levels of adherence are currently sub-optimal. (Bani et al., 2007; Ridner, McMahon, Dietrich, & Hoy, 2008; Rose, Taylor, & Twycross, 1991; Tidhar & Katz-Leurer, 2010)



## Understanding lymphoedema self-management



(IMS Model; DiMatteo, Haskard-Zolnierrek, & Martin, 2012)

## Understanding lymphoedema self-management

- **Information provision**  
(Bani et al., 2007)
- **Knowledge**  
(Ridner et al., 2011; Sherman & Koelmeyer, 2011)



## Understanding lymphoedema self-management



- **Consequences**  
(James, 2011; Sherman & Koelmeyer, 2013)
- **Control**
- **Self-efficacy**
- **Self-regulation**  
(Sherman & Koelmeyer, 2013)

## Understanding lymphoedema self-management



- **Financial cost**  
(James, 2011; Ridner et al., 2011)
- **Time management**  
(Ridner et al., 2011)
- **Physical barriers**  
(James, 2011; Newman, Brennan, & Passik, 1996; Ridner et al., 2011)

## Understanding lymphoedema self-management



## Questions?

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## **Appendix F – Accepted poster conference presentations**

### **Innovations in Cancer Treatment and Care Conference.**

October 17, 2014. Sydney, Australia.

#### **Predictors of psychological distress in women with breast cancer-related lymphedema**

*Living with lymphedema can have a negative psychosocial impact on an individual, including impaired quality of life, body image disturbance, and psychological distress. However, the factors that increase the risk of experiencing psychological distress are not known.*

**Authors:** J Alcorso (Lead) K A Sherman

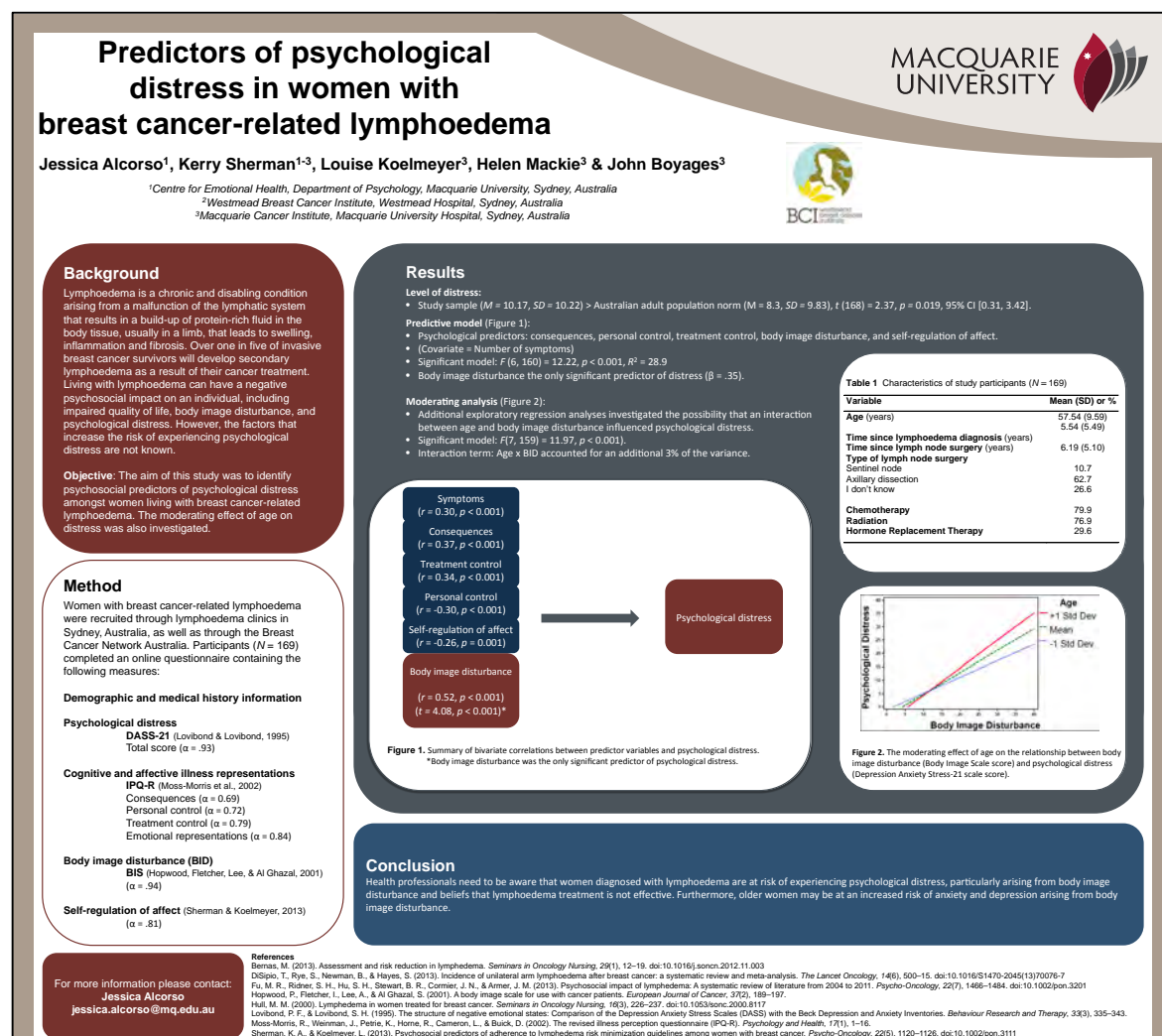
**Aims.** The aim of this study is to identify psychosocial predictors of psychological distress amongst women living with breast cancer-related lymphedema.

**Method.** Women with breast cancer-related lymphedema were recruited through lymphedema clinics in Sydney, Australia, as well as through the Breast Cancer Network Australia. Participants (N = 169) completed measures of psychological distress, cognitive and affective illness representations, body image disturbance, and self-regulation of affect.

**Results.** Number of symptoms, perceived consequences, perceived personal control, perceived treatment control, body image disturbance, and self-regulation of affect were identified as potential covariates of psychological distress. A multiple linear regression analysis was significant and revealed that 28.9% of the variance in psychological distress can be explained by the six covariates. However, only body image disturbance was a statistically significant predictor of psychological distress.



**Implications.** The results of this study suggest that women experiencing body image disturbance as a result of their lymphedema are at risk of psychological distress. These findings have implications for health professionals involved in the treatment of breast cancer-related lymphedema and for developing intervention strategies to support women in coping with the negative psychosocial impact of lymphedema.



**World Congress of Psycho-Oncology.**

July 28 – August 1, 2015. Washington, DC, USA.

*Internal funding Postgraduate Research Fund recipient.*

**Body image and psychological distress in women with breast cancer-related lymphedema**

Jessica Alcorso<sup>1\*</sup>, Kerry Sherman<sup>1,2</sup>

<sup>1</sup>Centre for Emotional Health, Department of Psychology, Macquarie University, Sydney, Australia

<sup>2</sup>Westmead Breast Cancer Institute, Sydney, Australia

**Purpose:** Breast cancer-related lymphedema can compromise a woman's physical and psychological functioning, including her body image. The aim of this study was to identify factors associated with psychological distress in women living with breast cancer-related lymphedema.

**Methods:** Australian women (N = 166) diagnosed with breast cancer-related lymphedema were recruited through a community-based breast cancer organisation and lymphedema treatment clinics. Participants completed an online survey assessing demographic and medical history information, psychological distress (Depression, Anxiety, Stress Scales), body image disturbance (Body Image Scale), lymphedema-related cognitions (IPQ-R), and perceived ability to self-regulate lymphedema-related negative affect.

**Results:** Mean psychological distress for this sample was significantly higher than for the Australian population norm. Number of symptoms of lymphedema, beliefs about the consequences and controllability of lymphedema, body image disturbance, and

perceived ability to self-regulate lymphedema-related negative affect were correlated with psychological distress. Multivariate regression analysis indicated that these correlates explain 31.8% of the variance in psychological distress; however, only body image disturbance was a statistically significant predictor of psychological distress.

**Conclusions:** Lymphedema therapists and other health professionals need to be aware that women diagnosed with lymphedema are at risk of experiencing psychological distress, particularly arising from 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.

**Research implications:** These findings are the first to investigate specific psychosocial factors associated with distress in women living with lymphedema. The identification of body image disturbance as the sole factor related to distress points to the need for interventions designed to assist women with coping with the bodily changes resulting from lymphedema, and in managing associated psychological distress.

**Practice implications:** Breast care nurses, lymphedema therapists and other health professionals involved in the care of women at risk of developing lymphedema, or who are currently living with lymphedema, 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 would benefit from additional support.

**Acknowledgement of funding:** This research was funded internally by Macquarie University, Sydney, Australia.

**Learning objective:** The participant shall be able to understand the psychosocial impact of breast cancer-related lymphedema on breast cancer survivors as well as identify the key factors associated with psychological distress in this population.



# Body image and psychological distress in women with breast cancer-related lymphedema

Jessica Alcorso<sup>1</sup> & Kerry A. Sherman<sup>1,2</sup>

<sup>1</sup> Centre for Emotional Health, Department of Psychology, Macquarie University, Sydney, Australia  
<sup>2</sup> Westmead Breast Cancer Institute, Westmead Hospital, Sydney, Australia

## Background

Lymphedema is a chronic and disabling condition arising from a malfunction of the lymphatic system that results in a build-up of protein-rich fluid in the body tissue, usually in a limb, that leads to swelling, inflammation and fibrosis. Over one in five of invasive breast cancer survivors will develop secondary lymphedema as a result of their cancer treatment. Living with lymphedema can have a negative psychosocial impact on an individual, including impaired quality of life, body image disturbance, and psychological distress. However, the factors that increase the risk of experiencing psychological distress are not known.

Objective: The aim of this study was to identify psychosocial factors associated with psychological distress in women living with breast cancer-related lymphedema, and determine whether age moderated the impact of these factors.

## Method

Australian women ( $N = 166$ ) diagnosed with breast cancer-related lymphedema were recruited through a community-based breast cancer organization and lymphedema treatment clinics in Sydney.

Participants completed an online survey assessing the following:

Demographics and medical history

Psychological distress: DASS-21 (Lovibond & Lovibond, 1995)

Depression ( $\alpha = 0.92$ ), Anxiety ( $\alpha = 0.79$ ), Stress ( $\alpha = 0.84$ )

Lymphedema-related illness representations: IPO-R (Moss-Morris et al., 2002)

Personal control ( $\alpha = 0.72$ ), Treatment control ( $\alpha = 0.79$ ), Consequences ( $\alpha = 0.88$ )

Self-regulation of affect (Sherman & Koelmeyer, 2013) ( $\alpha = .81$ )

Body image disturbance (BID): BIS (Hopwood, Fletcher, Lee, & Al Ghazal, 2001) ( $\alpha = .94$ )

## Results

- Participant characteristics are displayed in Table 1.
- The mean DASS-21 anxiety score ( $2.71$ ,  $SD = 3.32$ ) for this sample were significantly higher than for the Australian adult population norm ( $1.74$ ,  $SD = 2.78$ ) [33],  $t(661) = 3.70$ ,  $p < 0.001$ , 95% CI [0.46, 1.49].
- 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 lymphedema ( $M = 12.27$ ,  $SD = 8.03$ ) [12],  $t(218) = -4.51$ ,  $p < 0.001$ , 95% CI [-6.78, -2.25].
- Results of the multiple linear regression analyses were similar for depression [ $F(8, 159) = 12.28$ ,  $p < 0.001$ ,  $R^2 = .38$ ], anxiety [ $F(8, 159) = 7.25$ ,  $p < 0.001$ ,  $R^2 = .27$ ] and stress [ $F(8, 159) = 5.42$ ,  $p < 0.001$ ,  $R^2 = .21$ ], indicating an overall significant model for each outcome variable.
- For each distress subscale, body image disturbance was significantly associated with psychological distress. In addition, treatment control was significantly associated with stress scores.

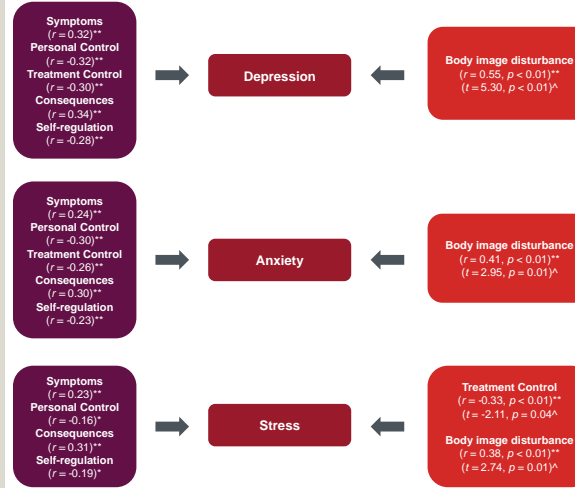


Figure 1. Summary of bivariate correlations between predictor variables and depression, anxiety and stress (DASS-21).

\*\*Correlation is significant at the 0.01 level (2-tailed). \*Correlation is significant at the 0.05 level (2-tailed)

^Significant predictor of distress variable in the regression analysis at the 0.01 level.

## References

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

Variable	Mean (SD) or %	Variable	Mean (SD) or %
Age (years)	58.04 (10.62)	Employment status (%)	
Education (%)		Full-time	30.8
High school or less	22.9	Part-time	23.7
Tertiary degree or more	38.5	Not employed	45.5
Income (%)		Time since diagnosis (years)	5.54 (5.49)
Less than \$50,000	29.1	Type of lymph node Surgery (%)	
\$50,000 - \$100,000	40.4	Sentinel node	10.7
More than \$100,000	30.5	Axillary	62.7
Marital status (%)		Received Chemotherapy (%)	79.9
Married/Partnered	79.9	Received Radiation (%)	76.9
Divorced/Separated	8.3	Received Hormone Replacement Therapy (%)	29.6
Single/Widowed	11.1	Number of symptoms*	5.45 (2.41)

\* Only number of symptoms was significantly associated with depression ( $r = 0.32$ ,  $p < 0.001$ ), anxiety ( $r = 0.24$ \*,  $p < 0.001$ ) and stress scores ( $r = 0.23$ ,  $p < 0.001$ ) at the 0.01 level (2-tailed).

## Moderation analyses

- Additional exploratory regression analyses investigated the possibility that an interaction between age and body image disturbance influenced psychological distress.
- The body image disturbance x age interaction was significant for depression and anxiety only (see Figure 2), whereby older women with more body image disturbance were more distressed.

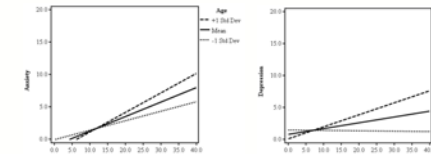


Figure 2. The moderating effect of age on the relationship between body image disturbance (Body Image Scale score) and depression and anxiety (DASS-21).

## Conclusion

Health professionals need to be aware that women diagnosed with lymphedema are at risk of experiencing psychological distress, particularly arising from body image disturbance and beliefs that lymphedema treatment is not effective. Furthermore, older women may be at an increased risk of anxiety and depression arising from body image disturbance.

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MACQUARIE  
University



**World Congress of Lymphology Conference.**

September 7 – 11, 2015. San Francisco, USA.

**PSYCHOSOCIAL FACTORS ASSOCIATED WITH PSYCHOLOGICAL  
DISTRESS IN WOMEN WITH BREAST CANCER-RELATED LYMPHEDEMA**

JESSICA ALCORSO<sup>1,2</sup>, KERRY A SHERMAN<sup>1,2</sup>, LOUISE KOELMEYER<sup>3</sup>, HELEN  
MACKIE<sup>3</sup>, JOHN BOYAGES<sup>3</sup>

<sup>1</sup>Centre for Emotional Health, Department of Psychology, Macquarie University,  
Sydney, Australia

<sup>2</sup>Westmead Breast Cancer Institute, Westmead Hospital, Sydney, Australia

<sup>3</sup>Macquarie University Cancer Institute, Macquarie University Hospital, Sydney,  
Australia

**Background/Purpose:** Previous research has shown that lymphedema impacts negatively on an individual from a psychosocial perspective, including psychological distress and body image disturbance, particularly for younger women. The aim of this study was to identify psychosocial factors associated with psychological distress in women with breast cancer-related lymphedema, and to determine whether age moderated the impact of these factors.

**Methods:** Australian women (N = 166) diagnosed with breast cancer-related lymphedema were recruited through a community-based breast cancer organisation and lymphedema treatment clinics. Participants completed an online survey assessing demographic and medical history information, psychological distress (depression, anxiety and stress), lymphedema-related cognitions (personal control, treatment control, consequences of lymphedema), perceived ability to self-regulate lymphedema-related

negative affect, and body image disturbance.

**Results:** Beliefs about the consequences and controllability of lymphedema, perceived ability to self-regulate negative affect, body image disturbance and number of lymphedema symptoms were correlated with depression, anxiety and stress scores.

Multivariate regression analyses indicated that only body image disturbance was significantly associated with depression, anxiety and stress, and treatment control was associated with stress. Moderation analyses identified age as a moderator of the relationship between body image disturbance and depression and anxiety.

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

# Psychosocial factors associated with psychological distress in women with breast cancer-related lymphedema

Jessica Alcorso<sup>1</sup>, Kerry A. Sherman<sup>1,2</sup>, Louise Koelmeyer<sup>3</sup>, Helen Mackie<sup>3</sup> & John Boyages<sup>3</sup>

<sup>1</sup> Centre for Emotional Health, Department of Psychology, Macquarie University, Sydney, Australia; <sup>2</sup> Westmead Breast Cancer Institute, Westmead Hospital, Sydney, Australia; <sup>3</sup> Faculty of Medicine and Health Sciences, Macquarie University, Sydney, Australia

## Background

Over one in five of invasive breast cancer survivors will develop secondary lymphedema as a result of their cancer treatment. Living with lymphedema can have a negative psychosocial impact on an individual, including impaired quality of life, body image disturbance, and psychological distress. However, the factors that increase the risk of experiencing psychological distress are not known.

## Objective

The aim of this study was to identify psychosocial factors associated with psychological distress in women living with breast cancer-related lymphedema, and determine whether age moderated the impact of these factors.

## Method

Australian women (N = 166) diagnosed with breast cancer-related lymphedema were recruited through a community-based breast cancer organization and lymphedema treatment clinics in Sydney. Participants completed an online survey assessing the following:

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Self-regulation of affect (Sherman & Koelmeyer, 2013) ( $\alpha = .81$ )

Body image disturbance (BID): BIS (Hopwood, Fletcher, Lee, & Al Ghazal, 2001) ( $\alpha = .94$ )

## Results

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- 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 lymphedema ( $M = 12.27$ ,  $SD = 8.03$ ) [12],  $t(218) = -4.51$ ,  $p < 0.001$ , 95% CI [-6.78, -2.25].
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Income (%)		Time since diagnosis (years)	5.54 (5.49)
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\$50,000 - \$100,000	40.4	Sentinel node	10.7
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Married/Partnered	79.9	Received Radiation (%)	76.9
Divorced/Separated	8.3	Received Hormone Replacement Therapy (%)	29.6
Single/Widowed	11.1	Number of symptoms <sup>a</sup>	5.45 (2.41)

<sup>a</sup> Only number of symptoms was significantly associated with depression ( $r = 0.32$ ,  $p < 0.001$ ), anxiety ( $r = 0.24$ \*,  $p < 0.001$ ) and stress scores ( $r = 0.23$ ,  $p < 0.001$ ) at the 0.01 level (2-tailed).

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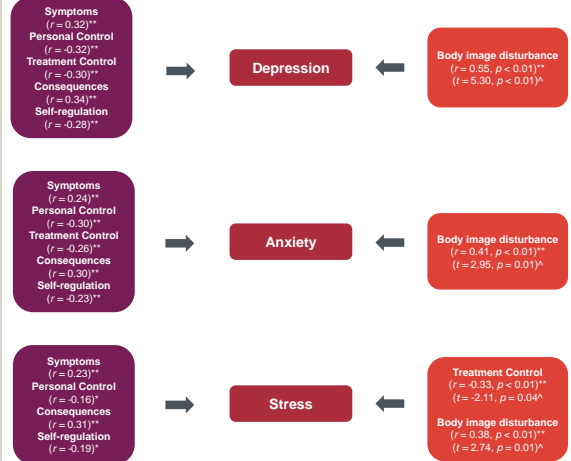


Figure 1. Summary of bivariate correlations between predictor variables and depression, anxiety and stress (DASS-21).

\*Correlation is significant at the 0.01 level (2-tailed). \*Correlation is significant at the 0.05 level (2-tailed)  
^Significant predictor of distress variable in the regression analysis at the 0.01 level.

## Moderation analyses

- Additional exploratory regression analyses investigated the possibility that an interaction between age and body image disturbance influenced psychological distress.
- The body image disturbance x age interaction was significant for depression and anxiety only (see Figure 2), whereby older women with more body image disturbance were more distressed.

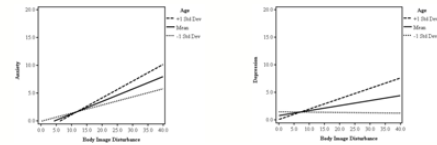


Figure 2. The moderating effect of age on the relationship between body image disturbance (Body Image Scale score) and depression and anxiety (DASS-21).

## Conclusion

Health professionals need to be aware that women diagnosed with lymphedema are at risk of experiencing psychological distress, particularly arising from body image disturbance and beliefs that lymphedema treatment is not effective. Furthermore, older women may be at an increased risk of anxiety and depression arising from body image disturbance.

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## **PERCEIVED BARRIERS TO ADHERENCE TO BREAST CANCER-RELATED LYMPHEDEMA SELF-MANAGEMENT**

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Australia

**Background/Purpose:** Lymphedema self-management is critical for maintaining treatment outcomes and slowing the progression of the illness. A range of factors including medical, psychosocial and economic may serve as barriers to self-management treatment adherence. The aim of this study was to quantitatively measure perceived barriers to lymphedema self-management of women with breast cancer-related lymphedema compared with perceptions of lymphedema therapists.

**Methods:** Australian women (N = 166) diagnosed with breast cancer-related lymphedema were recruited through a community-based breast cancer organization and lymphedema treatment clinics. Lymphedema therapists (N = 98) were recruited through an online registry. Participants completed an online survey assessing demographic information, medical history (affected women), lymphedema therapy practice details (therapists), and perceived barriers to adherence to lymphedema self-management (i.e., concerns about appearance, physical limitations, financial cost, time limitations, lack of social support, access to treatment, lack of information).

**Results:** Independent samples *t*-tests revealed that there was 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 barrier, therapists were significantly more likely to agree that it negatively impacts adherence, while affected women were more likely to disagree that it negatively impacts adherence.

**Conclusions:** Differences between affected women and therapists in beliefs about barriers to lymphedema self-management suggest a need for improvements in patient-provider communication. Health professionals working with women with breast cancer-related lymphedema should aim to have regular targeted discussions with their clients about potential barriers to self-management and strategies for overcoming these barriers.

# Perceived barriers to adherence to breast cancer-related lymphedema self-management

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## Background

- Over one in five of invasive breast cancer survivors will develop secondary lymphedema as a result of their cancer treatment.
- Self-management is critical for the effective maintenance of breast cancer-related lymphedema (BCRL), but previous research shows that levels of adherence are suboptimal, with less than one in five women completely adherent to their self-management regimen.
- In qualitative studies, women have reported a number of barriers to self-management of lymphedema, including financial cost (e.g., of compression garments), physical limitations, lack of time, limited social support and insufficient knowledge.

## Objective

- The aim of this study was to directly compare the perceptions of lymphedema therapists with those of women affected with BCRL regarding barriers to self-management adherence.

## Method

### Participants and procedure

Women (n = 162) diagnosed with BCRL were recruited through a community-based breast cancer organization (Breast Cancer Network Australia) and lymphedema treatment clinics in Sydney. Therapists (n = 98) were recruited through the Australasian Lymphology Association's (ALA) National Lymphoedema Practitioners Register (NLPR). Participants completed an online questionnaire.

### Measures

- Demographic information and medical history (i.e., time since lymphedema diagnosis and details about their breast cancer treatment).
- Lymphedema therapists were asked to provide information about their occupation and lymphedema therapy practice.
- Perceived barriers: Participants were asked to indicate how strongly they agreed or disagreed with each of seven barriers to self-management adherence. Each perceived barrier was measured using a 5-point Likert-type scale (0 = strongly disagree, 5 = strongly agree).

Table 1. Affected women with BCRL sample characteristics (n = 162).

Variable	Mean (SD) or %	Variable	Mean (SD) or %
Age (years)	57.33 (10.13)	Type of LN Surgery (%)	
Australian Aboriginal or Torres Strait Islander (%)	2	Sentinel node	12.8
Education (%)		Axillary	78.8
High school or less	22.2	I don't know	8.3
Some tertiary	38.3	Received Chemotherapy (%)	77.8
Tertiary degree or more	39.5	Received Radiation (%)	79.6
Income (%)		Received HRT (%)	41.4
Less than \$50,000	35.8	Time since lymphedema diagnosis (years)	5.12 (7.15)
\$50,000 - \$100,000	32.1	Lymphedema severity (%)	
\$100,000 - \$150,000	21.6	Stage 0 (Subclinical)	17.9
More than \$150,000	10.4	Stage 1 (Mild)	58.0
Marital status (%)		Stage 2 (Moderate)	22.2
Married/Partnered	80.2	Stage 3 (Severe)	1.2
Divorced/Separated	9.3	Unsure	0.6
Single	7.4		
Widowed	3.1		

Note: LN = Lymph node, HRT = Hormone replacement therapy

Table 2. Lymphedema therapist sample characteristics (n = 98)

Variable	Mean (SD) or %	Variable	Mean (SD) or %
Occupation (%)		Practice location within Australia - State (%)	
Physiotherapist	49	New South Wales	29
Massage Therapist	29	Queensland	20
Occupational Therapist	13	Victoria	17
Registered Nurse	9	South Australia	9
Years treating individuals with lymphedema	9.42 (6.04)	Western Australia	9
		Australian Capital Territory	3
		Northern Territory	3
		Tasmania	0

## Results

- Participant characteristics are displayed in Table 1 (affected women) and Table 2 (lymphedema therapists).
- A multivariate analysis of variance (MANOVA) was used to compare affected women's and lymphedema 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 negatively impacts adherence, while affected women were more likely to disagree that it negatively impacts adherence (Figure 1).

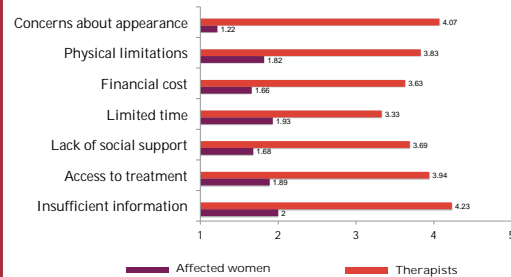


Figure 1. Patient and therapist mean ratings for perceived barriers to self-management (1 = strongly disagree, 5 = Strongly agree). For all factors  $p < 0.001$

## Conclusion

- This is the first study to directly compare the beliefs of women with breast cancer-related lymphedema with those of lymphedema therapists regarding perceived barriers to self-management adherence.
- As predicted, there was a significant difference between groups on the extent to which they agreed that each barrier negatively influences adherence.
- Therapists were significantly more likely to agree that each of the factors are salient barriers to adherence.
- In contrast, affected women were more likely to disagree that each potential barrier influenced adherence.
- This finding suggests that there is a disconnect between beliefs held by affected women and those of therapists and that there is a need for improvements in patient-provider communication.
- Lymphedema therapists should aim to have regular discussions with their clients about potential strategies for overcoming barriers to self-management.

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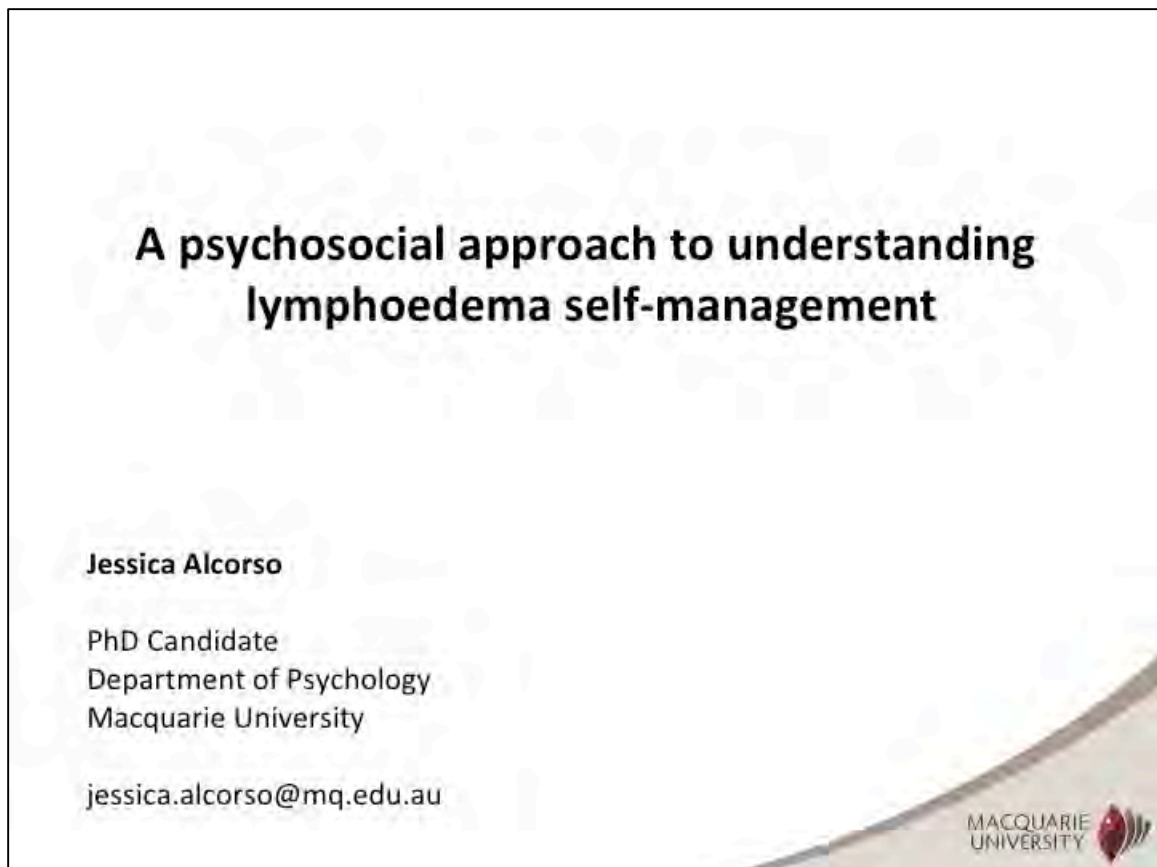
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## **Appendix G – Invited seminar presentations**

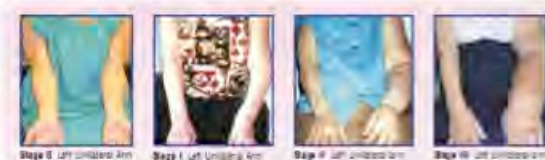
### **Macquarie University Cancer Institute Lymphoedema Seminar.**

September 23, 2014. Sydney, Australia.



# Introduction

- **What do we know about patient adherence to breast cancer-related lymphoedema self-management?**
  - Patient adherence is critical for maintaining treatment outcomes and helping to prevent or slow the progression of the illness. (Andersen, Højris, Erlandsen, & Andersen, 2000; Johnstone et al., 2006; Lasinski, 2013; Vignes et al., 2007)
  - Levels of adherence are currently sub-optimal. (Bani et al., 2007; Ridner, McMahon, Dietrich, & Hoy, 2008; Rose, Taylor, & Twycross, 1991; Tidhar & Katz-Leurer, 2010)



Source: ImpediMed

# Background

- Previous research suggests that psychosocial factors may influence general adherence to self-management guidelines. (James, 2011; Ridner et al., 2011)
- Breast cancer survivors and adherence to lymphoedema risk-management:
  - **Knowledge** (Bosompra et al., 2002; Sherman & Koelmeyer, 2011; Sherman et al., 2014)
  - **Self-efficacy and self-regulation of affect** (Sherman & Koelmeyer, 2013; Sherman et al., 2014)
  - **Perceived control and perceived consequences** (Sherman & Koelmeyer, 2013)
  - **Distress** (Sherman et al., 2014)

# Research Question

- *Aim:*
  - Determine if the factors underlying adherence in breast cancer survivors at-risk of developing lymphoedema also predict adherence in women who have developed breast cancer-related lymphoedema.



Source: en.hdyo.org



# Method

- *Participants*
  - English-speaking adult (18+ years) females diagnosed with breast cancer-related lymphoedema
  - Recruitment:
    - Breast Cancer Network Australia: Review & Survey Group
    - Lymphoedema Clinics:
      - ALAC
      - Mt Wilga Private Hospital
      - Therapy for Life



## Method

- *Procedure*

- Invitation to participate in a 20 minute online survey: in person, by post or e-mail.
  - URL to online survey provided via e-mail
- Response: 200 women consented to participate, 31 not included in final analysis due to incomplete data.
  - $N = 169$



Source: [live.surveymock.com](http://live.surveymock.com)



## Method

- *Measures*

- **Demographic and medical history information**
- **Knowledge**
  - (Sherman & Koelmeyer, 2013; Sherman et al., 2014)
- **Patient adherence**
  - Current clinical guidelines (NLN, 2011)
  - Consultation with lymphoedema therapists



## Method

- *Measures*

- **Illness beliefs and lymphoedema-related distress**

- Revised Illness Perception Questionnaire (IPQ-R)  
(Moss-Morris et al., 2002)

**Consequences** ( $\alpha = 0.69$ )

*My lymphoedema has major consequences on my life.*

**Personal control** ( $\alpha = 0.72$ )

*What I do can determine whether my lymphoedema gets better or worse.*

**Treatment control** ( $\alpha = 0.79$ )

*The negative effects of my lymphoedema can be prevented by my treatment.*

**Emotional representations** ( $\alpha = 0.84$ )

*I get depressed when I think about my lymphoedema.*

## Method

- *Measures*

- **Self-efficacy and self-regulation of affect**

- (Sherman & Koelmeyer, 2013; Sherman et al., 2014)

**Self-efficacy**

*I believe I have the ability to make the necessary lifestyle changes to carry out the recommended self-care practices to manage my lymphoedema.*

**Self-regulation of affect** ( $\alpha = .81$ )

*I believe that I am able to calm myself down when anxious or worried about lymphoedema.*

*I believe I am able to limit the amount of stress experienced as a result of lymphoedema.*

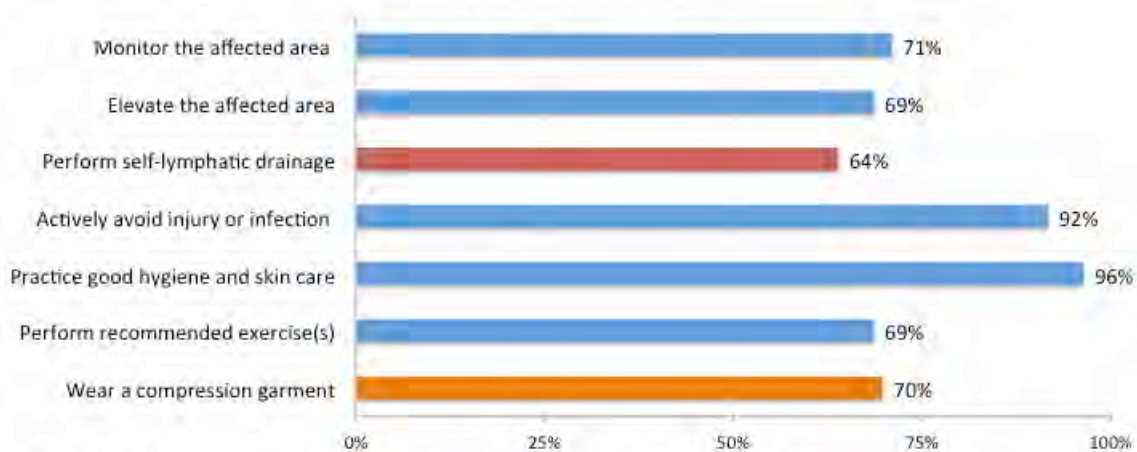


## Results

**Table 1. Characteristics of study participants (*n* = 169)**

Variable	Mean ( <i>SD</i> ) or %
Age (years)	57.54 (9.59)
Time since lymphoedema diagnosis (years)	5.54 (5.49)
Time since lymph node surgery (years)	6.19 (5.10)
Type of lymph node surgery	
Sentinel node	10.7
Axillary	62.7
I don't know	26.6
Chemotherapy	79.9
Radiation	76.9
Hormone Replacement Therapy	29.6

## Results



**Figure 1. Percentage of participants adhering to each self-management behaviour as prescribed by their therapists.**

- $M = 5.29$  ( $SD = 1.39$ ) behaviours adhered to out of a total of seven.
- 19.5% of participants adhered to all seven behaviours.

## Results

Table 3. Bivariate correlations between the outcome (adherence) variable and psychosocial variables.

Variable	1	2	3	4	5	6	7	8	M	SD
1. Adherence	–	-0.13*	-0.03	0.05	-0.14*	0.11	0.09	0.05	5.29	1.39
2. Knowledge		–	0.40***	0.28***	0.01	0.07	0.03	0.14	5.41	1.28
3. Self-efficacy			–	0.64***	0.11*	0.04	0.04	-0.01	3.12	0.87
4. Self-regulation				–	0.33***	-0.14	-0.23***	-0.30***	5.38	1.95
5. Personal control					–	-0.29***	0.24***	-0.36***	19.76	2.19
6. Treatment control						–	0.56***	0.46***	16.09	3.24
7. Consequences							–	0.45***	15.34	3.18
8. Distress								–	15.75	5.00

\*\*\*  $p < 0.01$  (2-tailed)

\*\*  $p < .05$

\*  $p < .10$

- Chemotherapy ( $r = 0.15$ ,  $p = 0.05$ )
- HRT ( $r = 0.17$ ,  $p = 0.031$ )
- Time since lymphedema diagnosis ( $r = 0.20$ ,  $p = 0.009$ )

## Results

Table 4. Multiple linear regression analysis to determine factors predictive of adherence to lymphedema self-management strategies.

	Unstandardized Coefficients		Standardized Coefficients			
	B	Std. Error	Beta	t	p	95% CI
Total adherence	7.599	1.032		7.366	.000	(5.56, 9.64)
Chemotherapy	.527	.254	.159	2.075	.040	(0.03, 1.03)
Hormone Replacement Therapy	.425	.195	.163	2.176	.031	(0.04, 0.81)
Time Since Diagnosis	-.031	.017	-.136	-1.798	.074	(-0.07, 0.01)
Personal Control	-.099	.048	-.156	-2.089	.038	(-0.19, 0.01)
Knowledge	-.142	.082	-.131	-1.731	.085	(-0.31, 0.02)

- Overall significant model,  $F(5, 163) = 4.37$ ,  $p = 0.001$
- Personal Control was a significant predictor of adherence ( $t = -2.09$ ,  $p = 0.038$ ).

## Discussion

- Overall level of adherence moderate:
  - Only 1 in 5 women performing all self-management behaviours as frequently as recommended (i.e., 100% adherent)
    - Highest: Skin care
    - Lowest: Self-lymphatic drainage, compression



Source: [dev.infoflympo.ca](http://dev.infoflympo.ca)

## Discussion

- Psychosocial factors that predict adherence to breast cancer-related lymphoedema risk-management behaviours do not explain a substantial amount of the variance in adherence to self-management for women with lymphoedema.
  - Similarities: Personal control and knowledge.



Source: [www.thecancerhelpblog.com](http://www.thecancerhelpblog.com)



## Discussion

- Other potential factors underlying adherence:
  - **physical limitations** (James, 2011; Newman, Brennan, & Passik, 1996; Ridner et al., 2011)
  - **financial cost of treatment** (James, 2011; Ridner et al., 2011)
  - **social isolation** (James, 2011)
  - **time management** (Radina, Armer, & Stewart, 2014; Ridner et al., 2011)
- Other chronic illnesses that involve self-management regimes
  - E.g., diabetes and patient-provider communication (Heisler et al., 2002; Piette, Schillinger, Potter, & Heisler, 2003)
  - Limitations

# Thank you! Questions?

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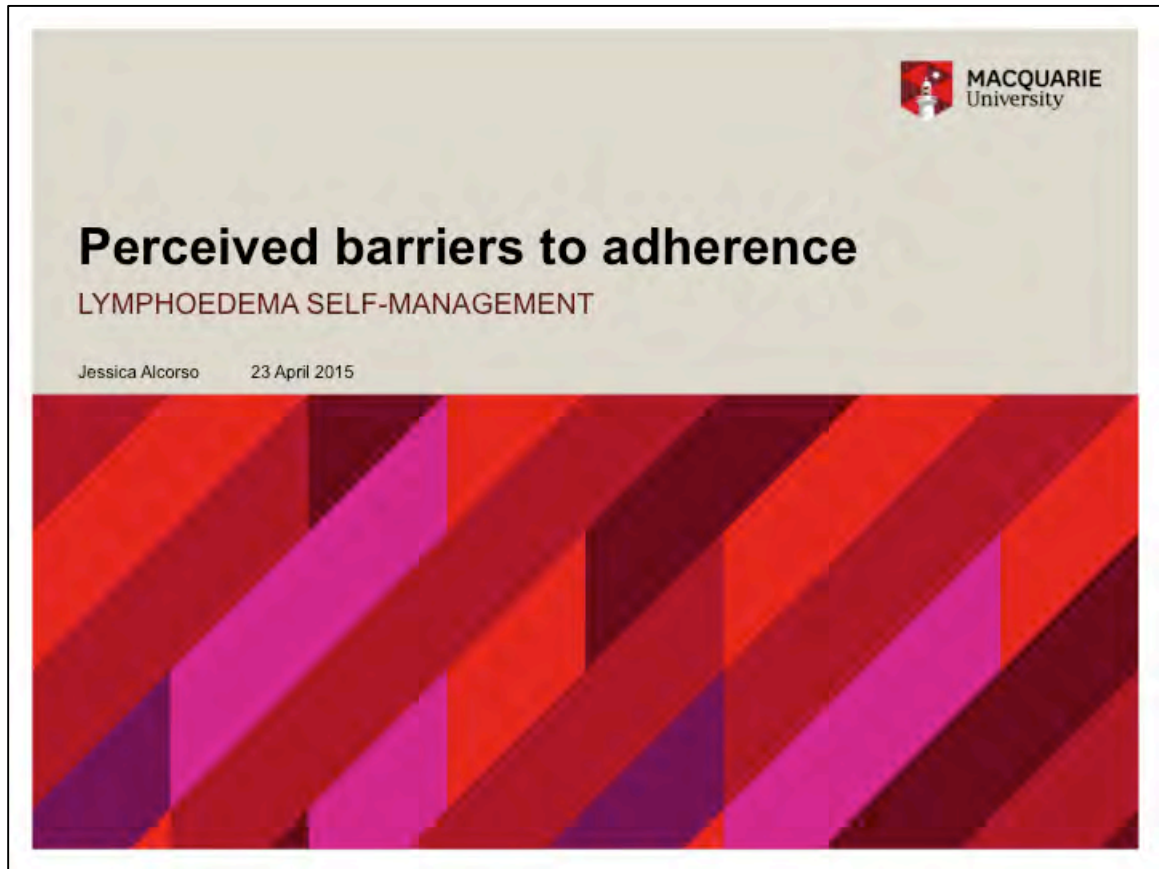
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**Macquarie University Lymphoedema Seminar.**

April 23, 2015. Sydney, Australia.



# Introduction

## RATIONALE



### Why is it important to study psychosocial predictors of adherence?



- Demographic and medical history factors do not explain a significant amount of the variance in self-management behaviours  
Chemotherapy, HRT, symptoms, time since diagnosis
- What about individuals' thoughts and emotions and beliefs about lymphoedema?

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# Introduction

## STUDY AIMS



### Are the perceptions of lymphoedema therapists and those of women with BCRL consistent when considering perceived barriers to self-management?



**Perceived barriers:** a person's estimation of the level of challenge of social, environmental and economic obstacles to a specified behaviour (e.g., wearing a compression garment).

- Qualitative findings: Financial cost<sup>1,2</sup>, physical limitations<sup>1,2</sup>, lack of time<sup>2,3</sup>, limited social support<sup>1</sup>, and insufficient knowledge<sup>2</sup>.
- Also: women frequently report concerns about their appearance related to compression garments<sup>4-6</sup> and difficulty accessing treatment<sup>7</sup>.

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## Method

### PARTICIPANTS AND PROCEDURE



#### Women with BCRL

- English-speaking adult women diagnosed with breast cancer-related lymphoedema
- BCNA and lymphoedema clinics
- 20min online questionnaire

#### Therapists

- Physiotherapists, occupational therapists, registered nurses and massage therapists
- ALA National Lymphoedema Practitioners Register (NLPR)
- 10min online questionnaire

From: *BC Breast Cancer Health* | Department of Physiotherapy | Faculty of Health Sciences

## Method

### MEASURES



#### Sample characteristics

- Demographic information
- Medical history
- Occupation
- Lymphoedema therapy practice (for Therapists)



#### Perceived barriers to self-management adherence

- Concerns about appearance
- Physical limitations
- Financial cost
- Time limitations
- Lack of social support
- Access to treatment
- Insufficient information



From: *BC Breast Cancer Health* | Department of Physiotherapy | Faculty of Health Sciences

# Results

## SAMPLE CHARACTERISTICS



### Women with BCRL (n = 166)

- **Age** (years): 58.04 (10.62)
- **Education:** 77.1% some university or more
- Majority **married** (79.9%) and **employed** (54.5%)
- **Time since lymphoedema diagnosis** (years): 5.54 (5.49)
- **Type of lymph node surgery:**
  - axillary (62.7%)
  - sentinel node (10.7%)
  - unknown (26.6%)
- **Breast cancer treatment:**
  - chemotherapy (79.9%)
  - radiation (76.9%)
  - HRT (29.6%)

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# Results

## SAMPLE CHARACTERISTICS



### Therapists (n = 98)

- **Occupation:**
  - Physiotherapist (49%)
  - Massage Therapist (29%)
  - Occupational Therapist (13%)
  - Registered nurse (9%)
- **Practice location within Australia**
  - New South Wales (29%)
  - Queensland (20%)
  - Victoria (17%)
  - South Australia (9%)
  - Western Australia (9%)
  - Northern Territory (3%)
  - Australian Capital Territory (0%)
  - Tasmania (0%)
- **Experience** (years): 9.42 (6.04)

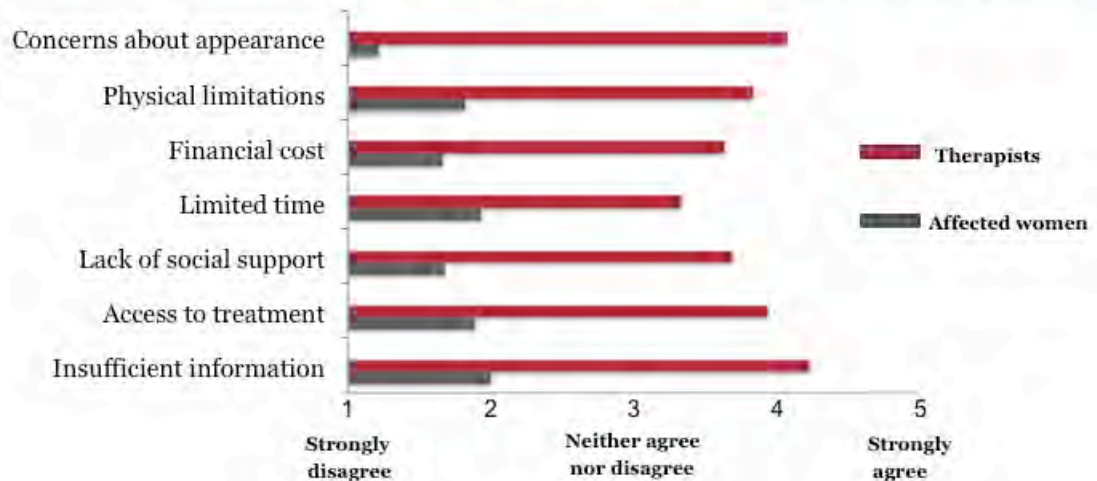
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# Results

## KEY FINDINGS



### Affected women and therapist ratings for perceived barriers to self-management



From: *BR International Health* | Department of Psychology | Faculty of Human Sciences

# Results

## KEY FINDINGS



### Affected women and therapist ratings for perceived barriers to self-management

Barrier to adherence	Affected women (n = 166)	Therapists (n = 98)	t	df	p value
	M (SD)	M (SD)			
1. Concerns about appearance	1.22 (1.17)	4.07 (0.75)	16.91	241	< .001
2. Physical limitations	1.82 (0.93)	3.83 (0.89)	16.94	242	< .001
3. Financial cost	1.66 (1.03)	3.63 (1.03)	14.67	242	< .001
4. Limited time	1.93 (0.78)	3.33 (0.95)	12.08	242	< .001
5. Lack of social support	1.68 (0.81)	3.69 (0.71)	19.98	241	< .001
6. Access to treatment	1.89 (0.98)	3.94 (0.88)	16.61	242	< .001
7. Insufficient information	2.00 (0.88)	4.23 (0.78)	20.32	242	< .001

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## Discussion



- Findings suggest a disconnect between women with BCRL and therapists such that therapists may not be aware of the key factors influencing women's adherence.



- **Limitations:**
  - Measure of perceived barriers not validated
  - Other potential barriers not measured

## Conclusion

### IMPLICATIONS FOR RESEARCH AND PRACTICE



- Focus on communication between women with BCRL and health professionals about barriers to self-management and strategies to overcome them.



- Future research: Aim to identify what women with BCRL perceive as the most influential barriers to adherence.





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