

Living with Lymphoedema

Prof Kerry Sherman

Lifespan, Health & Wellbeing
Research Centre
Centre for Emotional Health
School of Psychological Sciences
Macquarie University
Sydney, Australia

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Sydney - Macquarie University

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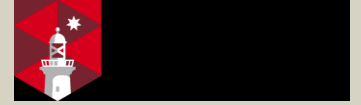


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Beate Ditzen
beate.ditzen@uni-heidelberg.de
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This presentation



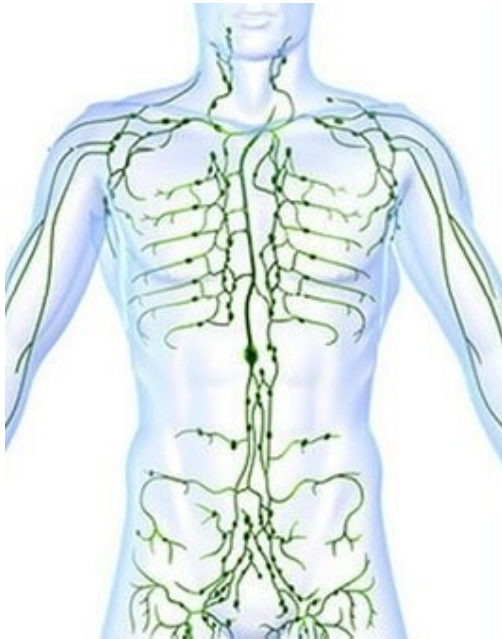
What do people **think and feel** about lymphoedema?

Why is this important?

Quality of life impacts of lymphoedema



What is lymphoedema?



Chronic condition

Accumulation of excessive amounts of protein-rich **lymph fluid** in the tissue resulting in swelling:

- Limb(s)
- Trunk
- Breast
- Head and neck
- Genital area

exceeds the capacity of lymphatic circulation

What is Lymphoedema?

Primary – genetic risk

Secondary - damage to lymphatics

- cancer surgery
- radiation treatment
- wounds, trauma and/or tissue damage
- infection (e.g., cellulitis and fungal infections)



Breast cancer-related lymphoedema risk factors

Togawa et al. (2014)

N=666

29% reported lymphoedema

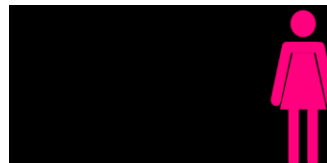
- Mastectomy
- Chemotherapy
- > 10 lymph nodes removed (vs. none)
- BMI \geq 30
- Hypertension (vs. none)

Showalter et al. (2014)

N=295 breast cancer survivors
(some with BCRL and others at risk)

Exposure to 30 potential risk factors at 3-month intervals for 1 year

- Sauna use
- Arm trauma (cut)
- Asian ethnicity



Lymphoedema Risk factors

Supportive Care in Cancer (2023) 31:18
<https://doi.org/10.1007/s00520-022-07508-2>

REVIEW



Risk factors of unilateral breast cancer-related lymphedema: an updated systematic review and meta-analysis of 84 cohort studies

Aomei Shen^{1,2,3} · Qian Lu^{1,2} · Xin Fu^{1,2} · Xiaoxia Wei^{1,2} · Liyuan Zhang⁴ · Jingru Bian⁴ · Wanmin Qiang³ · Dong Pang^{1,2}

BCRL Risk Factors: Systematic review and meta-analysis

Incidence 22%

Weight increase 1.073/kg gained

Larger tumour size

Stage II and III > I

ALND 3.1 times SNLB

Hypertension

Chemotherapy

Radiotherapy

Post-surgery complications

Inadequate finance

Protective

Breast reconstruction

Adequate finance

No association

Lack of exercise

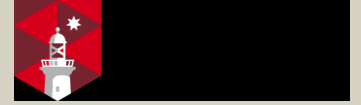
Smoking

Diabetes

Marital status

Tamoxifen use

(Shen et al., 2023)



How do the patients you care for respond to hearing about lymphoedema?



I couldn't cope with having something else go wrong....it would be devastating to get lymphedema after everything I've been through with cancer

It's ok.....after cancer, lymphoedema is not such a big deal



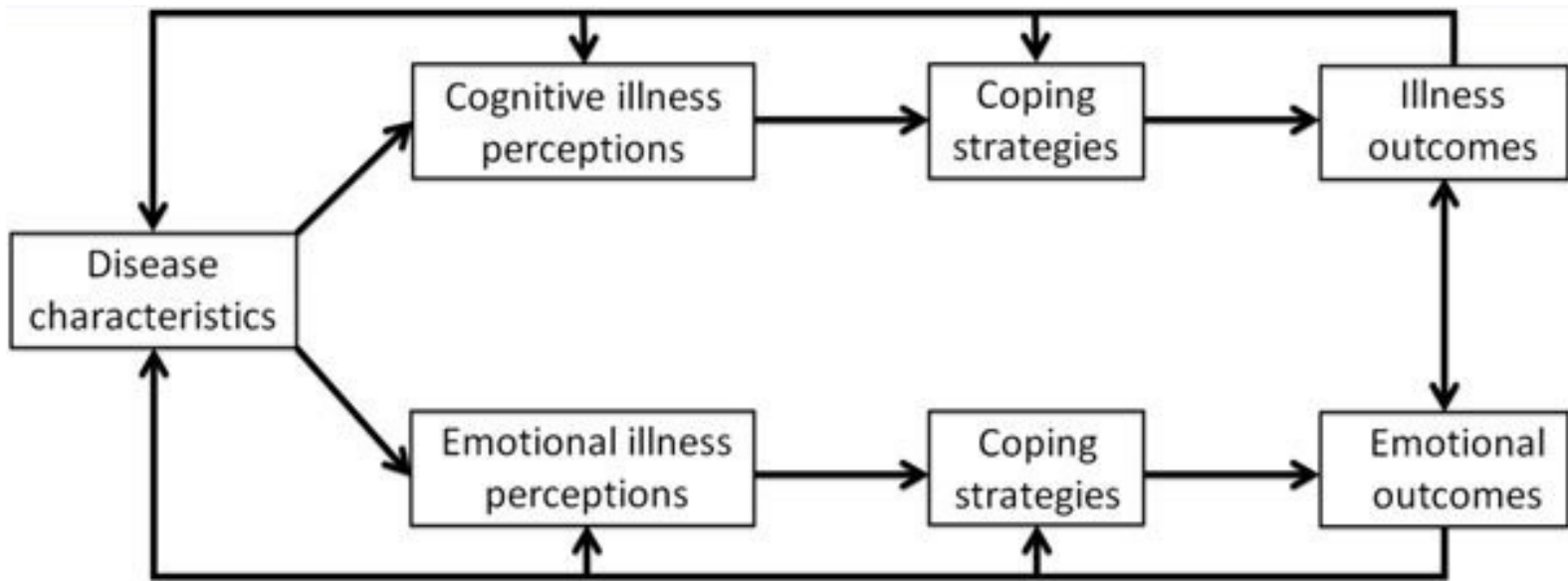
lymphoedema

I'm not worried about the stock market because I don't understand it.

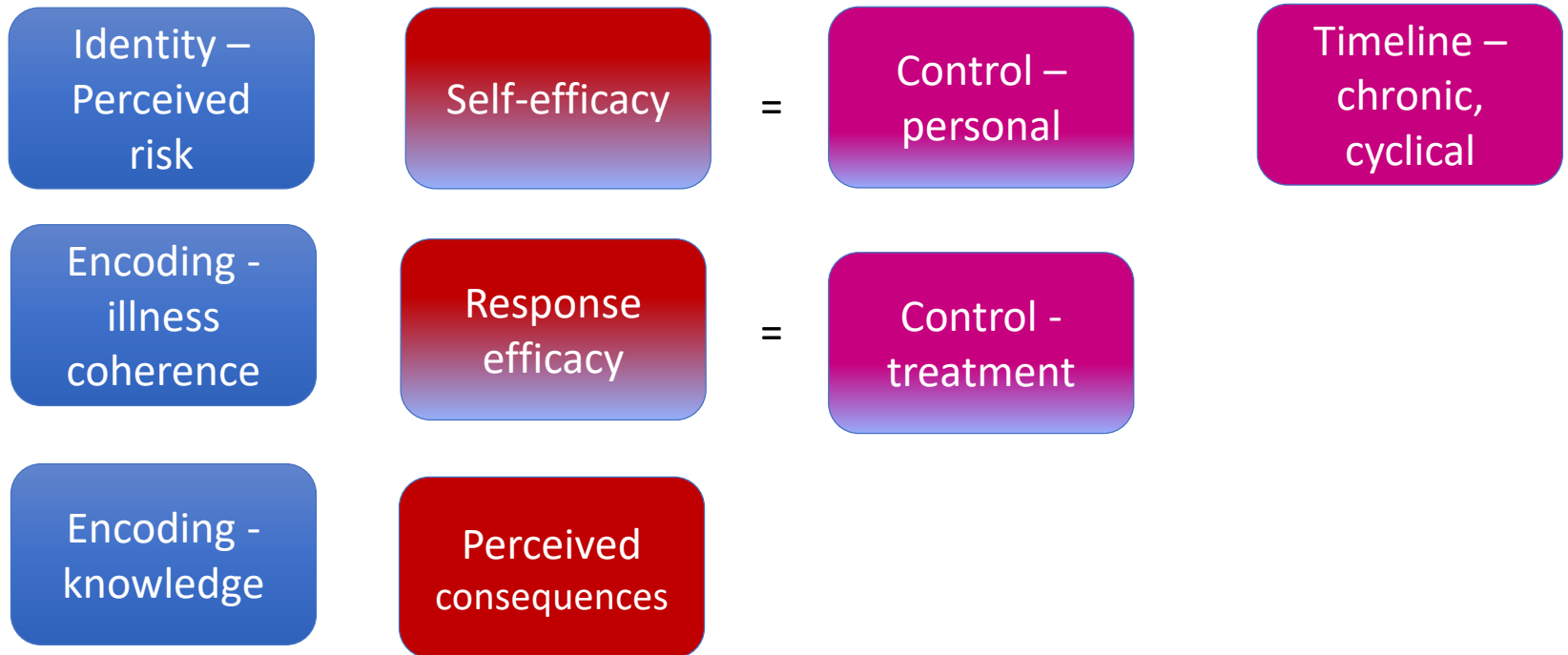


som ee cards

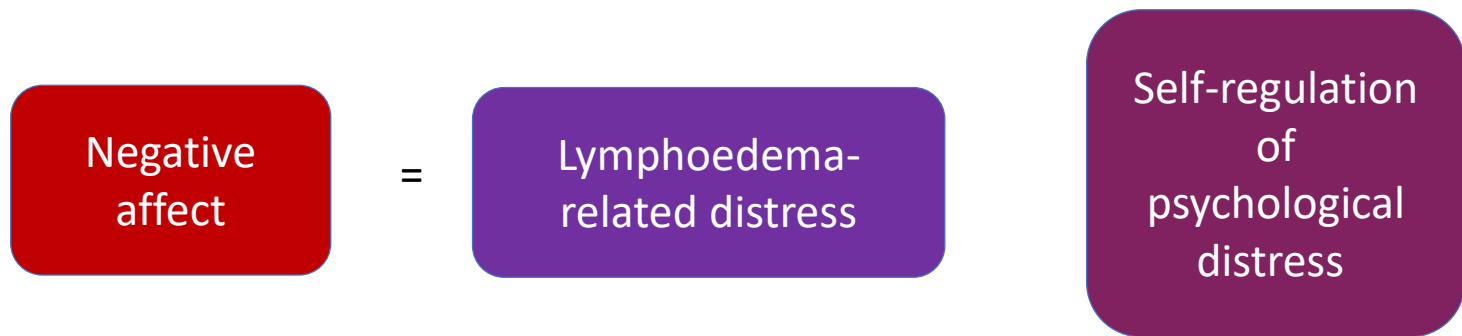
Psychological representations of lymphoedema: A self-regulation perspective



A self-regulation perspective: Cognitive representations of lymphoedema



A self-regulation perspective: Affective representations of lymphoedema





Breast Cancer Related Lymphoedema cognitive and affective responses



Cognitive and affective representations of breast cancer-related lymphoedema



Sherman & Koelmeyer (2013) – at risk



Sherman, Miller et al. (2015) - at risk



Alcorso, Sherman et al. (2016) – diagnosed



BCI westmead
breast cancer
institute



TEMPLE HEALTH

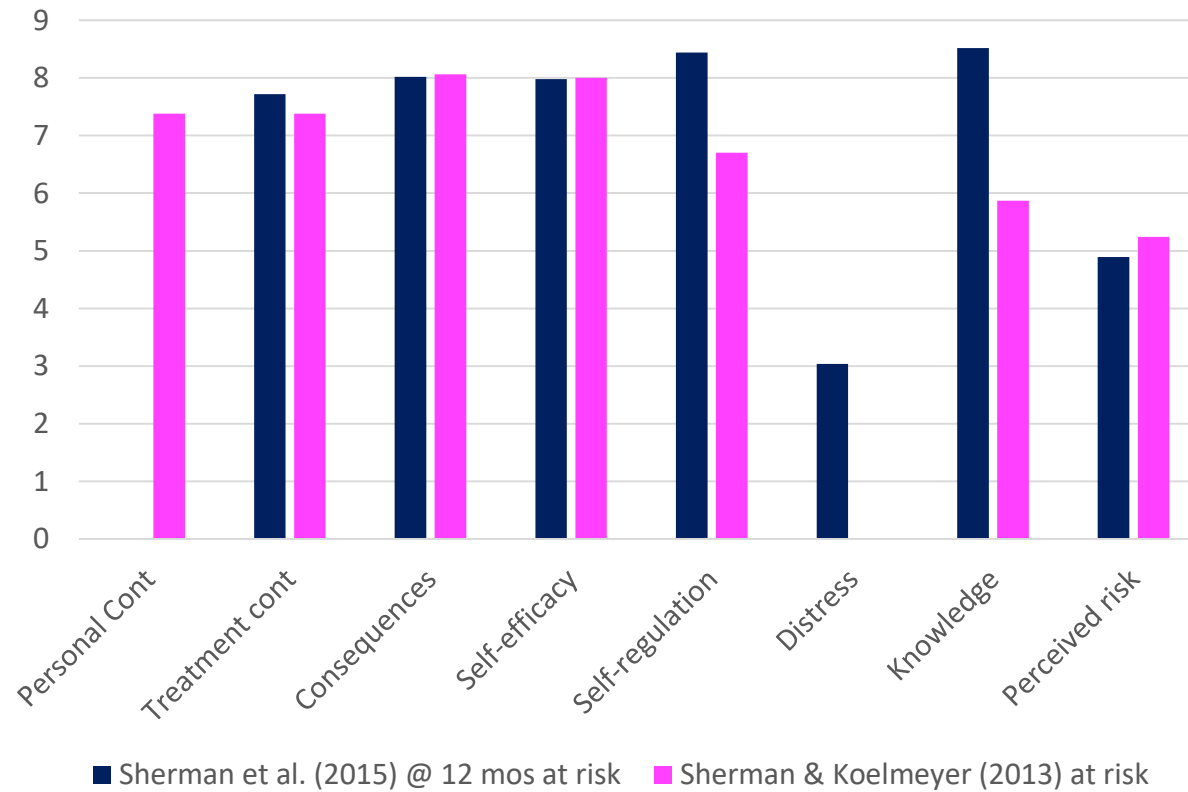
Online surveys

Recruited from:

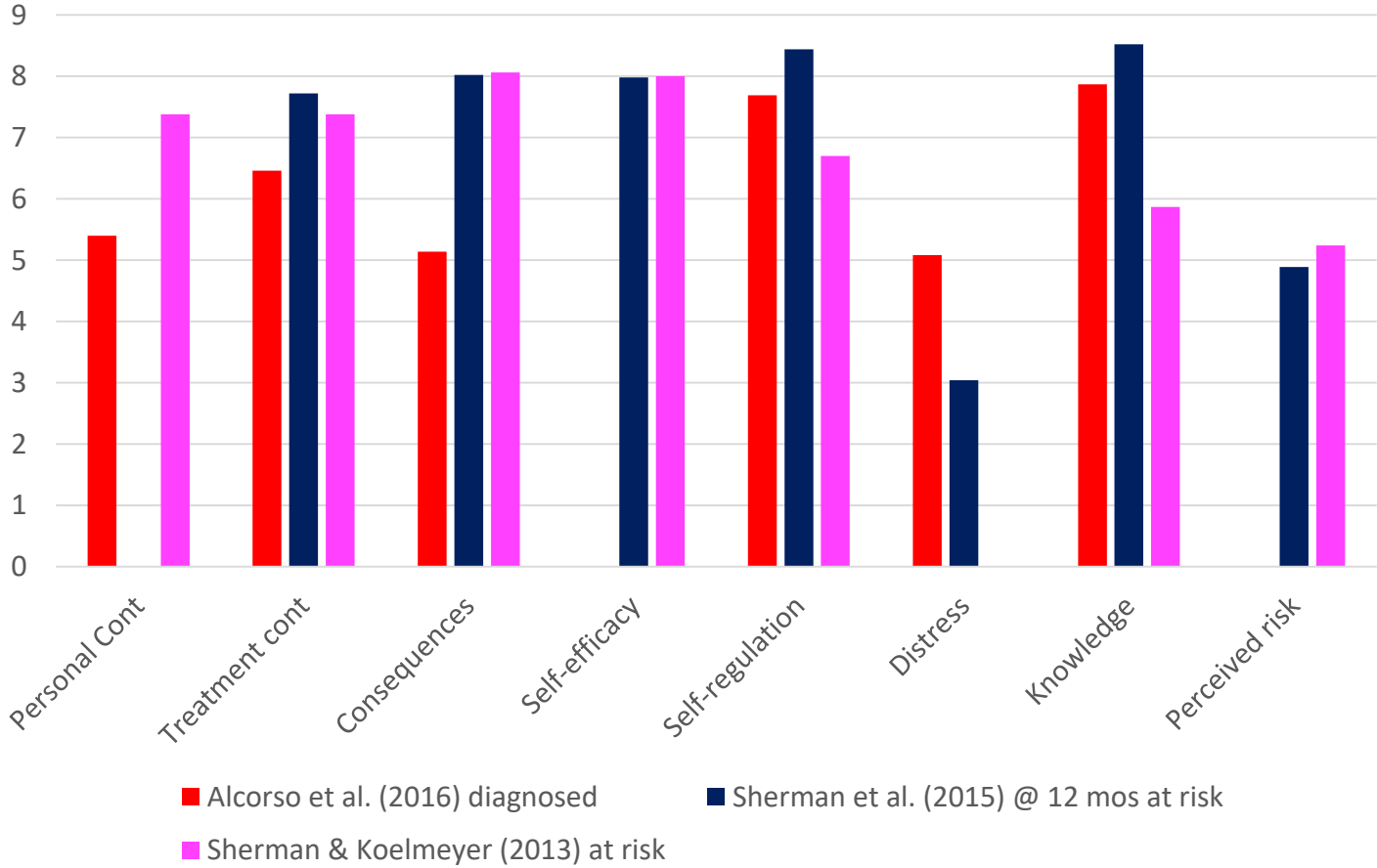
- breast cancer clinics
- consumer organisations
- lymphoedema clinics



Cognitive and affective representations: Lymphoedema risk



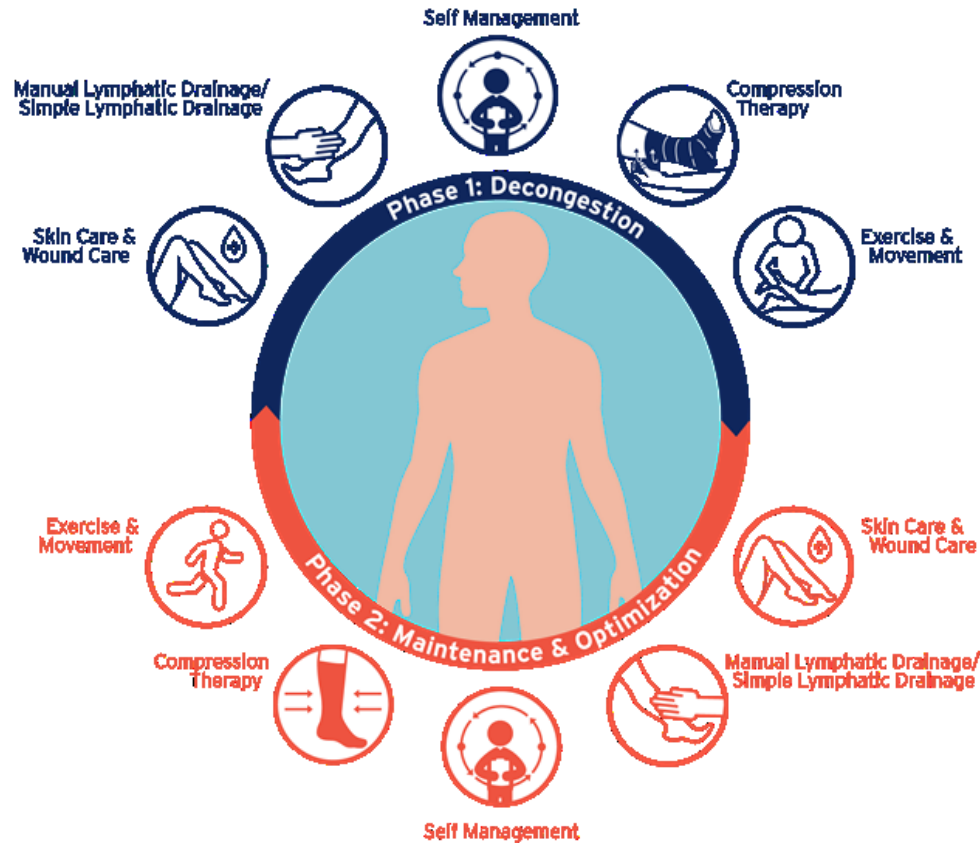
Cognitive and affective representations: Lymphoedema and lymphoedema risk



Challenge of lymphoedema management

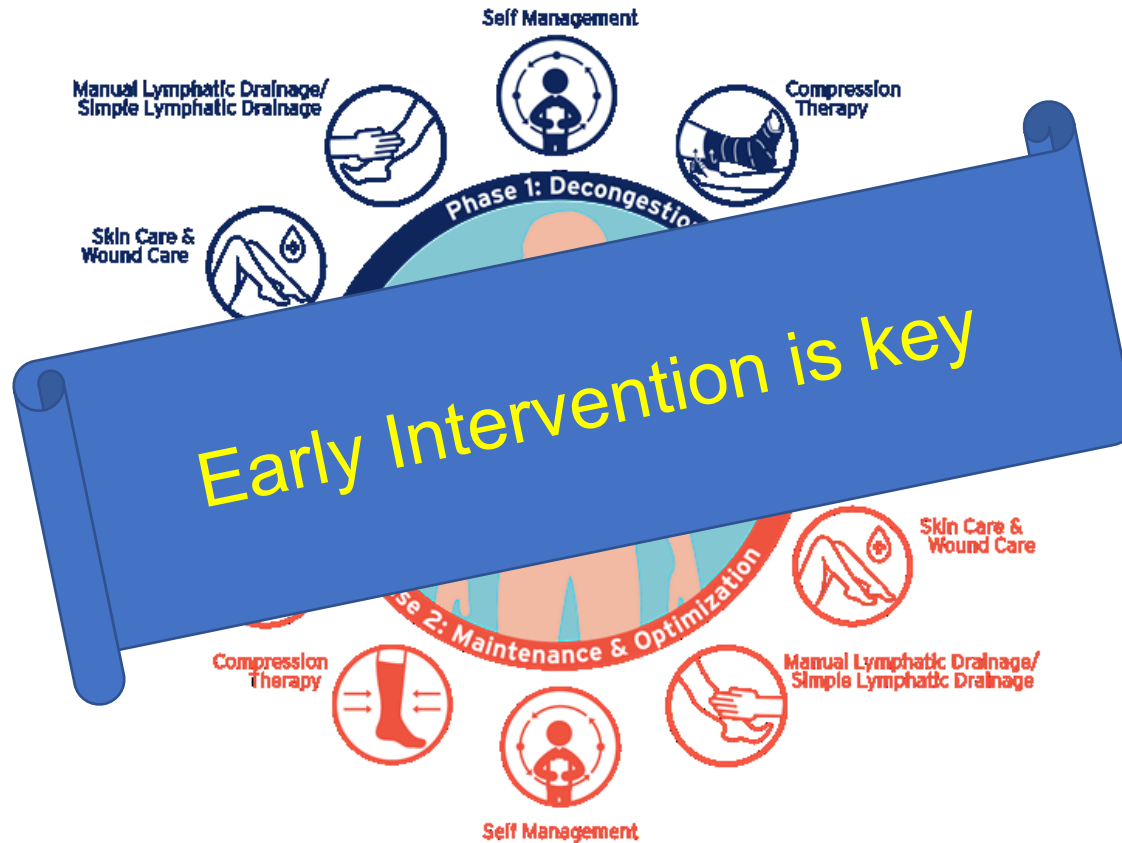


Lymphoedema management



lifelong, time-consuming and laborious

Lymphoedema management



lifelong, time-consuming and laborious

Lymphoedema self-management



- Clinical therapy – costly, sporadic
- Self-care strategies
- Minimise risk of symptom flare-ups
- Requires motivation and persistence
- Relies on effective self-regulation

Self-care strategies



- Skin and nail care (moisturising, avoiding trauma)
- Compression garment use
- Wearing gloves for gardening, housework
- Protection from excessive heat
- Insect repellent
- Regular exercise
- Seeking medical advice if symptoms arise
- Avoid tight clothing and jewellery

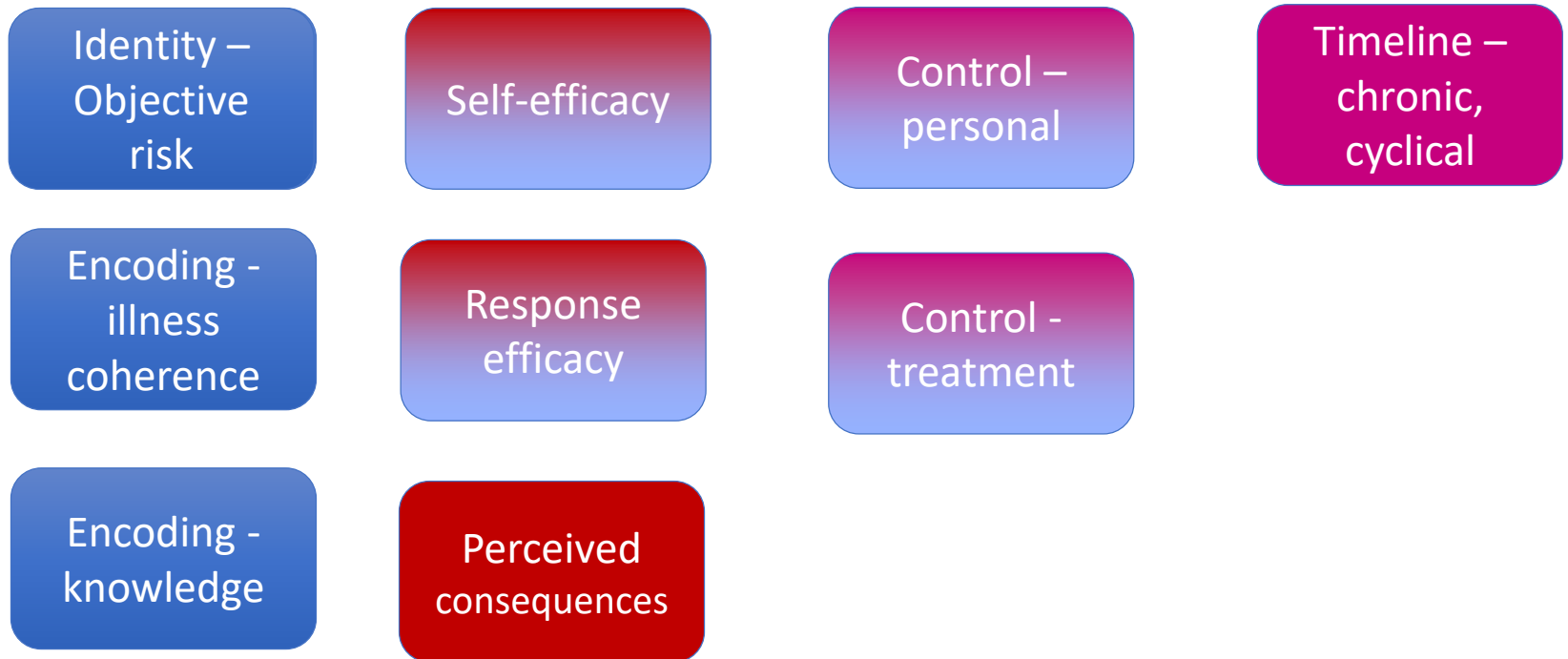


What cognitive and affective factors are related to adherence of self-management strategies?



Psychological responses to lymphedema risk:

Cognitive



(Miller & Diefenbach, 1998)

Psychological responses to lymphedema risk: *Affective*

Negative
affect

Lymphoedema-
related distress

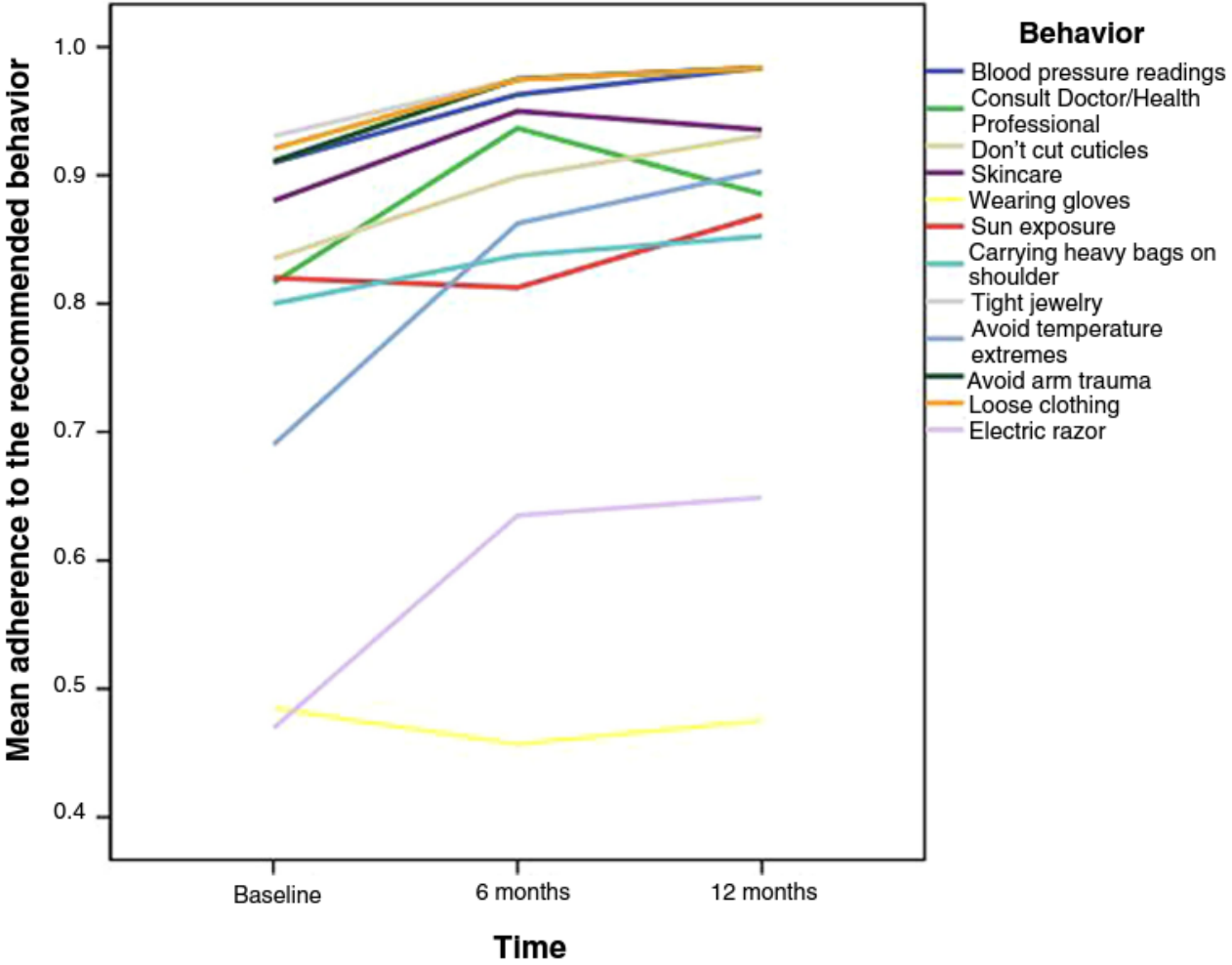
Self-
regulation

(Miller & Diefenbach, 1998)

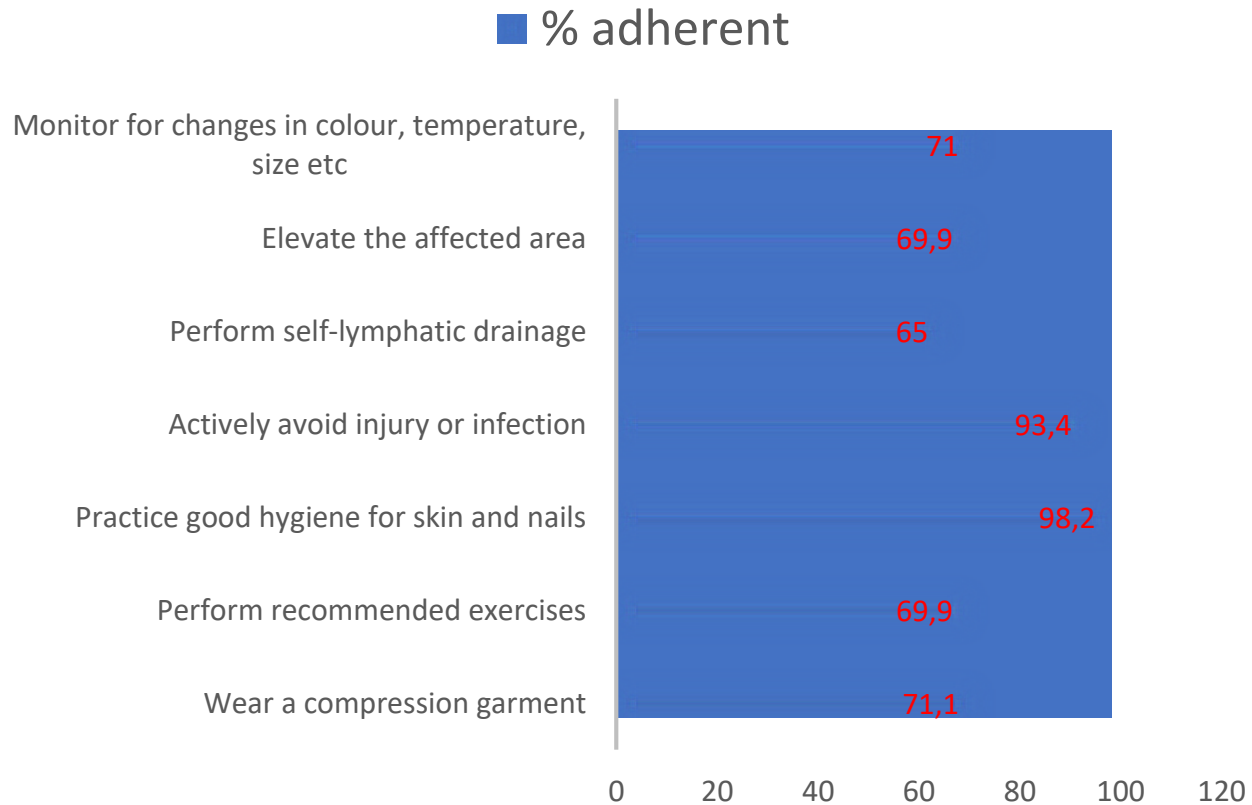


At-risk population adherence

Over time...
↓ Distress
↑ Knowledge

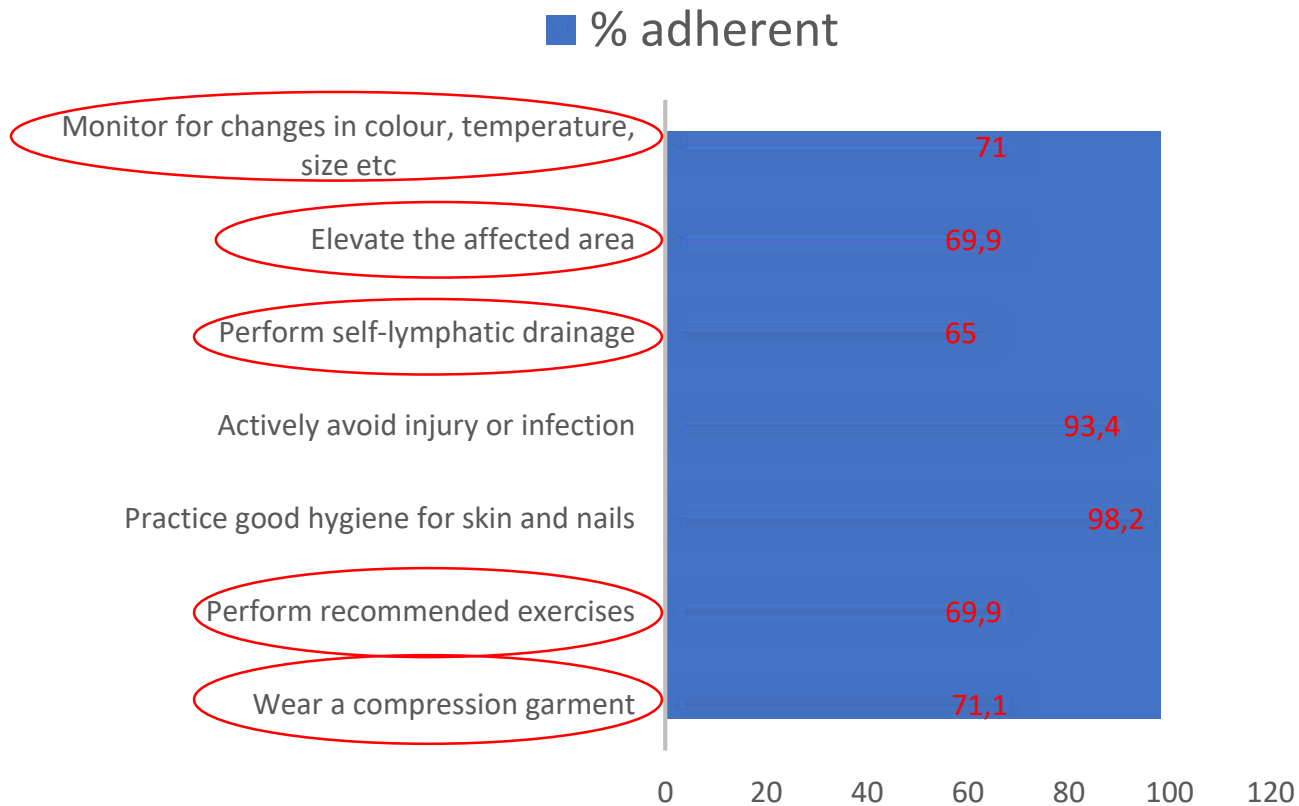


Diagnosed population adherence



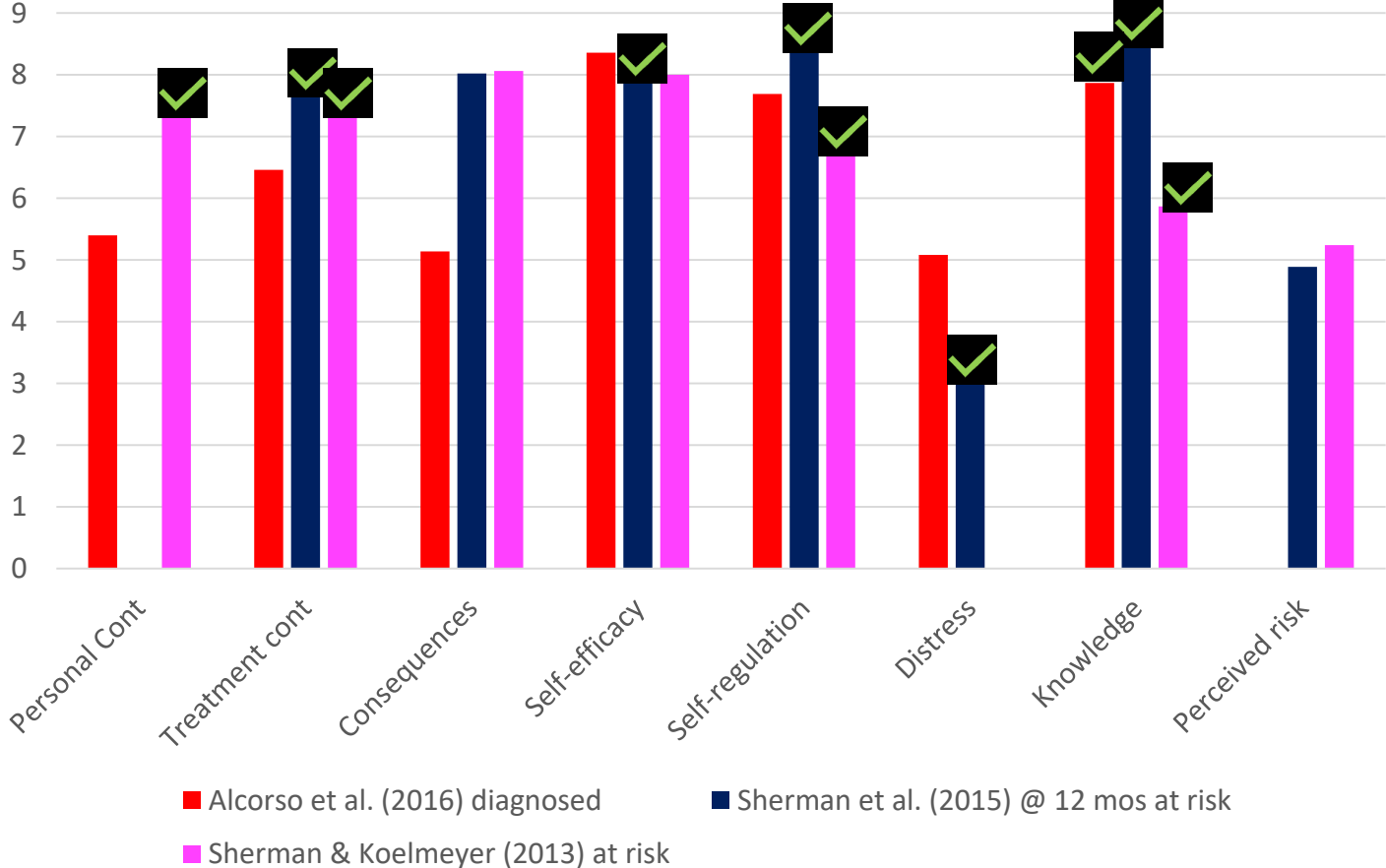
(Alcorso, Sherman et al., 2016)

Diagnosed population adherence

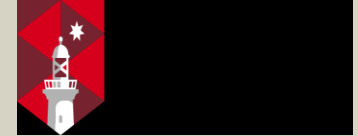


(Alcorso, Sherman et al., 2016)

Cognitive and affective representations and adherence



*Lower distress



What cognitive and affective factors are associated with willingness to seeking medical advice?



Patient Education and Counseling

Volume 101, Issue 3, March 2018, Pages 445-451



Research paper

Factors associated with professional healthcare advice seeking in women at risk for developing breast cancer-related lymphedema

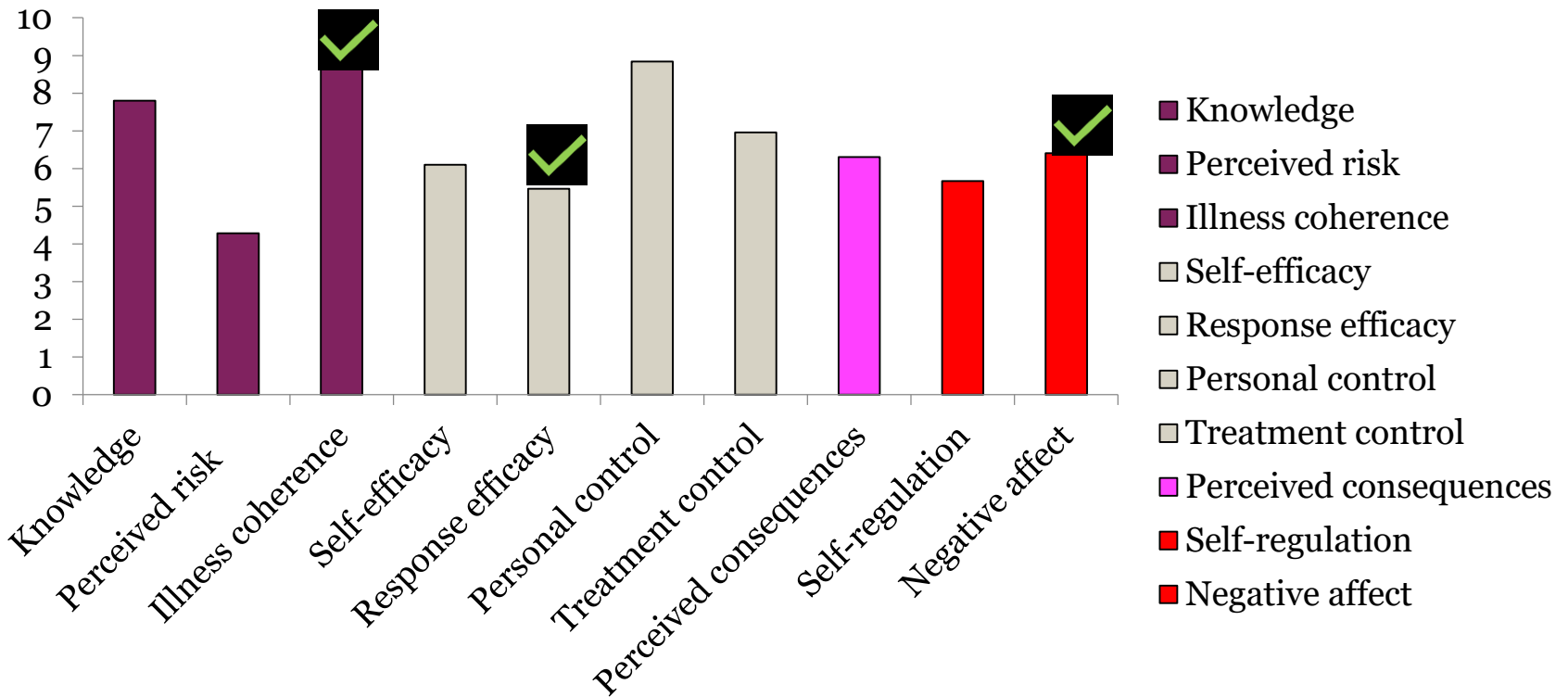
[Kerry A. Sherman](#)^{a b}  , [Christopher J. Kilby](#)^{a b}, [Elisabeth Elder](#)^a, [Sheila H. Ridner](#)^c

“Are you consulting with a health professional immediately if you have any slight increase of swelling in the affected arm, hand, fingers, or your chest wall?”

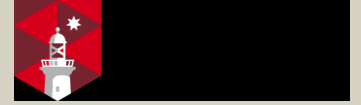
Only 60% were seeking medical advice if symptomatic



Adherence: “Are you *consulting with a health professional* immediately if you have any slight increase of swelling in the affected arm, hand, fingers, or your chest wall?”



*Greater negative affect



Which information sources are most influential in adherence to self-management strategies?



Adherence and information sources

- N= 106
- SLNB = 54
- ALND = 52; higher risk

- Adherence to 12 risk minimization behaviours

Wear gloves when gardening
Avoiding arm/hand trauma
Avoiding excessive heat
Using an electric razor
Consulting a Dr when symptomatic



(Sherman & Koelmeyer, 2011)

Encoding -
knowledge

Identity –
objective risk

- High and increased over 3 months
($F[1, 91] = 6.12, p = 0.015$)
- No difference by lymphoedema risk

	SLNB	ALND
$T_{0\text{ know}}$	16.3 (3.0)	16.92 (2.44)
3-mo _{know}	18.07 (1.84)	17.36 (2.37)

From where was lymphoedema information sourced?

Table 4. Lymphedema Information Sources Used by Patients Recently Diagnosed With Breast Cancer

Information Source	Baseline (N = 105)				Three Months (N = 98)				χ^{2a}	p
	Using Source		Not Using Source		Using Source		Not Using Source			
	n	%	n	%	n	%	n	%		
Given brochure on lymphedema and risk minimization	63	60	42	40	68	69	30	31	1.35	0.65
Attended allied health lymphedema information session	4	4	101	96	8	8	90	92	1.16	0.15
Clinic surgeon or oncologist	31	30	74	70	50	51	48	49	10.99	0.001
Clinic breast care nursing staff	55	52	50	48	72	73	26	27	5.74	0.001
Cancer Council New South Wales	45	43	60	57	62	63	36	38	11.25	0.001
Internet searching	13	12	92	88	19	19	79	81	18.41	0.0118
Local library	2	2	103	98	3	3	95	97	0.067	0.8
Family history of breast cancer ^b	41	39	59	56	–	–	–	–	–	–
Family history of lymphedema ^b	29	28	64	61	–	–	–	–	–	–

^a Using McNemar test

^b Because of missing data, sample size varies.

Risk minimisation behaviours

28% non adherent

High adherence
9.53 out of 12

No difference by
risk level

Greater knowledge:
greater adherence

($r = 0.5$, $p = 0.0001$)



Which information sources most influenced adherence?



Regression: Information from **nursing staff** and **3-mth lymphedema knowledge**
($F[13, 61] = 3.49, p = 0.0001$)



Are lymphoedema therapists and patients on the same page when it comes to self-management?



Perceived barriers to adherence to self-management: Patients vs. Clinicians

Barrier	Patient (n=162)	Clinician (n=98)
Appearance concerns	2.13 (0.95)	4.07 (0.75)
Physical limitations	1.91 (0.83)	3.83 (0.89)
Financial cost of garments	1.82 (0.88)	3.63 (1.03)
Insufficient time	1.94 (0.92)	3.33 (0.95)
Lack of social support	1.70 (0.73)	3.69 (0.71)
Access difficulties	1.94 (0.92)	3.94 (0.88)
Lack of knowledge	2.05 (0.80)	4.23 (0.78)

(Alcorso, Sherman et al., 2016b)

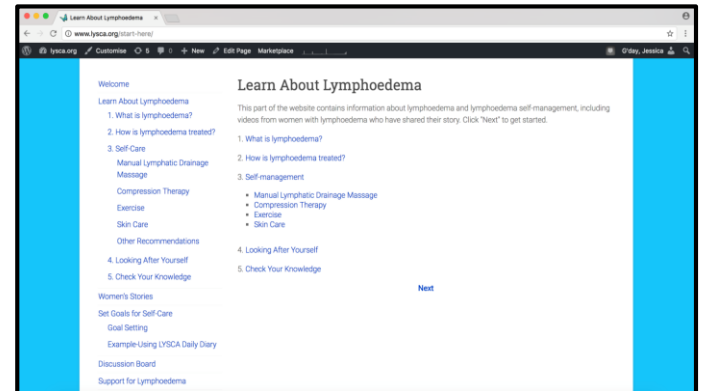
How can we enhance awareness and control beliefs for adherence?



LYSCA (LYmphoedema Self-CARE)

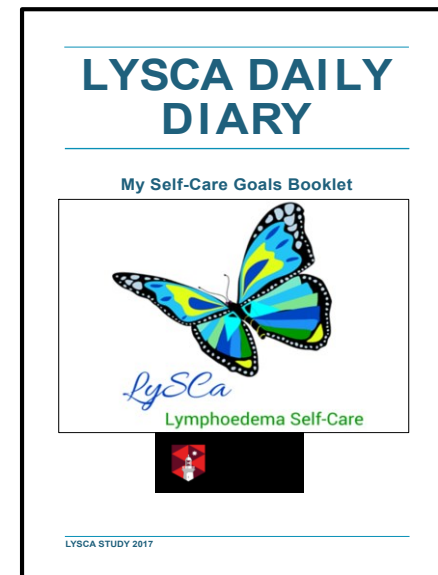
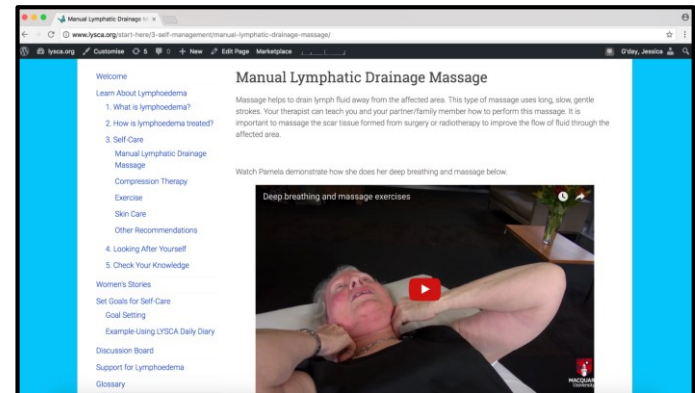


Web-based	Aim	Goals
psycho-educational intervention	facilitate lymphoedema self-care by enhancing self-care self-efficacy	Set and track achievable goals – diary booklet



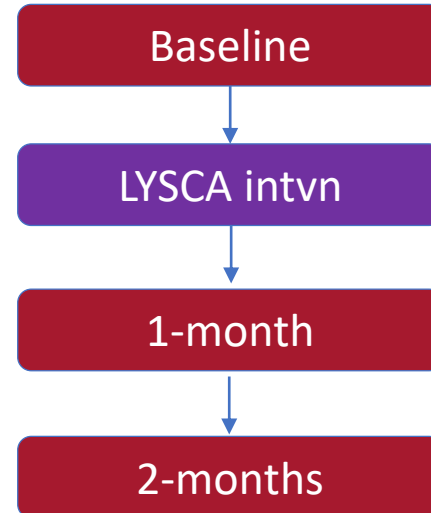
LYSCA (Lymphoedema Self-Care)

- **Learn about Lymphoedema** - video and text-based information about lymphoedema and self-care practices
- **Women's Stories** - videoed interviews with women living with lymphoedema
- **Setting Goals for Self-Care** – information about the importance of goal setting for health behaviour change and guidance on the goal setting process
- **Discussion Forum** - connect with other LYSCA users



Pilot Study Method

- $N = 97$ enrolled
- Women, medically diagnosed with BCRL
- Lymphoedema clinics
- Breast Cancer Network Australia
- Australia New Zealand Lymphoedema Registry
- Pre-post design



Measures

- Lymphoedema self-care **self-efficacy** (Sherman et al., 2015)
- **Self-efficacy** for managing chronic disease (Lorig et al., 2001)
- Lymphoedema symptom intensity and **distress** (LSIDSA-V2, Ridner & Dietrich, 2015)
- **Adherence to self-care** (Alcorso et al., 2016)
- Lymphoedema-related **cognitions and affect** (IPQ-R)
- User acceptability (e.g., website is easy to navigate)

Sample characteristics

Table 1: Sample Characteristics (N=97)

Age	59.12 (9.41)
Education	
High school/ Vocational	48.4%
University	51.6%
Marital status	
Partnered	73.2%
Income	
< \$50 000	28%
\$50 000 - \$100 000	30%
> \$100 000	20%
Not disclosed	22%
Experience with websites	
None	10.3%
Little	16.5%
Moderate	28.8%
High	28.9%
Very high	15.5%

Lymphoedema Diagnosis	
Stage 0	5.2%
Stage 1	48.5%
Stage 2	40.2%
Stage 3	4.1%
Time since lymphoedema diagnosis	5.50 years (4mths – 22 yrs)
Area affected	
Arm only	31.6%
Arm and hand	45.9%
Chest	2.0%
Chest and arm	5.9%
Chest, arm and hand	12.2%

Main Outcomes

	Mean	SD	<i>F</i>	<i>p</i>
Self-care Self-efficacy¹				
Baseline	3.65	0.77		
One Month	3.57	0.96	3.72	0.027
Two Months	3.90	1.02		
Self-Efficacy for Managing Chronic Disease²				
Baseline	6.31	2.88		
One Month	6.70	3.07	4.27	0.016
Two Months	6.86	3.17		
Symptom Intensity & Distress³				
Baseline	1.88	1.85		
One Month	1.60	1.97	7.46	0.001
Two Months	1.40	2.03		
Adherence to Self-Care⁹				
Baseline	6.32	1.66		
One Month	6.09	1.88	1.57	0.210
Two Months	6.40	1.97		

Cognitive and Affective Representations

	Mean	SD	F	p
Negative affect				
Baseline	17.35	6.21		
1-Month	16.73	6.75	4.86	0.009
2-months	15.92	6.92		
Illness Coherence⁵				
Baseline	19.94	5.54		
1-Month	19.55	5.95	3.29	0.041
2-Months	20.561	6.10		
Consequences⁶				
Baseline	18.57	6.22		
1-Month	18.61	6.70	1.08	0.344
2-Months	18.08	6.84		
Timeline Acute/Chronic⁷				
Baseline	25.01	4.04		
1-Month	25.49	4.50	1.43	0.245
2-Months	25.42	4.60		
Personal Control⁷				
Baseline	22.33	4.88		
1-Month	22.67	5.32	0.38	0.682
2-Months	22.48	5.54		
Treatment Control⁸				
Baseline	16.68	3.20		
1-Month	17.21	3.69	1.40	0.251
2-Months	17.06	3.89		

User Acceptability

	Mean	SD
Overall impression		
I want to look at all sections of the website	4.09	0.75
The topic of this website is interesting	4.23	0.72
I would be happy to return to this website	4.15	0.73
I would be happy to continue using the daily diary	3.57	0.96
Layout and design		
The website is well organised	4.07	0.67
The website is easy to navigate	4.19	0.55
The daily diary is clear and easy to read	4.35	0.54
Information and Content		
Information in the website is clear	4.14	0.64
Information in the website is easy to understand	4.16	0.62
When I look at the website I know what to do next	4.07	0.63
Information in the daily diary is easy to understand	4.22	0.58

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LYSCA users

	One Month	Two Months
Website Only	10.0%	20%
Diary Only	16.7%	34%
Both	60%	32%

“I feel comfortable with my body now”

“Because of the diary, my lymphoedema has improved dramatically and I can see the difference when I do my massage every day”

“I now do my arm exercises and self-massage on a daily basis instead of now and then”

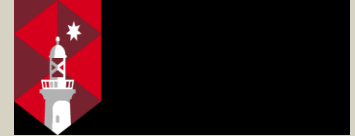
LYSCA non-users

	One Month	Two Months
Neither diary nor website	13.3%	14.0%

“busy with children and daily activities”

“my cancer returned”

“I am not good with diaries”



Lessons learned about adherence

Individual beliefs and emotional responses to lymphoedema do impact self-management

Knowledge and awareness is important, but so too is the perception of self-efficacy and controllability

Emphasise early-detection/early-treatment approaches

Managing distress through promoting positive self-regulatory strategies through self-care is also important

Quality of life impacts of lymphoedema



Self-identity: Body image

VOLUME 36 · NUMBER 19 · JULY 1, 2018

JOURNAL OF CLINICAL ONCOLOGY

ORIGINAL REPORT

Reducing Body Image–Related Distress in Women With Breast Cancer Using a Structured Online Writing Exercise: Results From the My Changed Body Randomized Controlled Trial

Kerry A. Sherman, Astrid Przedziecki, Jessica Alcorso, Christopher Jon Kilby, Elisabeth Elder, John Boyages, Louise Koelmeyer, and Helen Mackie

Baseline and diagnosed with BCRL:

- Body image distress – 12.89 (8.68) – clinically significant[#]
- Depression – 5.89 (4.44) – mild^{*}
- Anxiety – 5.07 (3.33) – mild^{*}

[#]Hopwood et al. (2000); ^{*}(Lovibond & Lovibond, 1995);

Sexual distress and BCRL

Winch, Sherman et al (2015)

Qualitative interviews: N=17



Sexual concerns arising from BCRL exacerbated existing concerns from breast cancer

Key factors:

swelling severity and location

wearing a compression garment

body image concerns (BCRL and BC)

their partner's acceptance and supportiveness

Sexual distress and BCRL

Winch, Sherman et al (2015)

Communication

Few were asked about sexual issues by a HP

Most were unwilling to discuss sexual concerns with HPs, friends, or family



BCRL may accentuate sexual issues caused by breast cancer, but most women were reluctant to discuss issues with anyone other than their partner

Sexual distress: Lower limb lymphoedema

(Winch, Sherman et al., 2016)

- Qualitative study ($N = 19$ women) [primary $n=11$; secondary $n=8$]
- Mean age 56 years
- Sexual concerns arising from lower limb lymphoedema

Themes reflecting lymphedema's impact:

- Attractiveness and Confidence (Publicly Unattractive, Privately Unconfident, Lymphedema or Aging?) describing women's central concern.

Women were self-deprecating and sarcastic in describing the appearance of an enlarged “lovely leg,” “sausage toes,” and “sexy [compression] stocking”

“You feel a little bit like a freak. You are different, you look different.”

Long Term QoL impacts



- What is the impact of BCRL up to 10 years after breast cancer treatment?

(n = 244 patients with BCRL; n = 823 patients without BCRL)

- Patients with BCRL diagnosis had significantly poorer HRQoL than patients without BCRL:
 - physical function
 - mental health
 - social role functioning
 - BCRL severity was not a key factor

(Jørgensen et al., 2021)



QoL impacts

Significant adverse impact – body image, sexual and psychological distress
Self-management demands ongoing vigilance and ability to manage distress
Psychological intervention – self-compassion



Mange tak!

