

Psychological perspective on the quality of life of women with lipoedema

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Lymf
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Lymf- och lipödemförening

Acknowledgments



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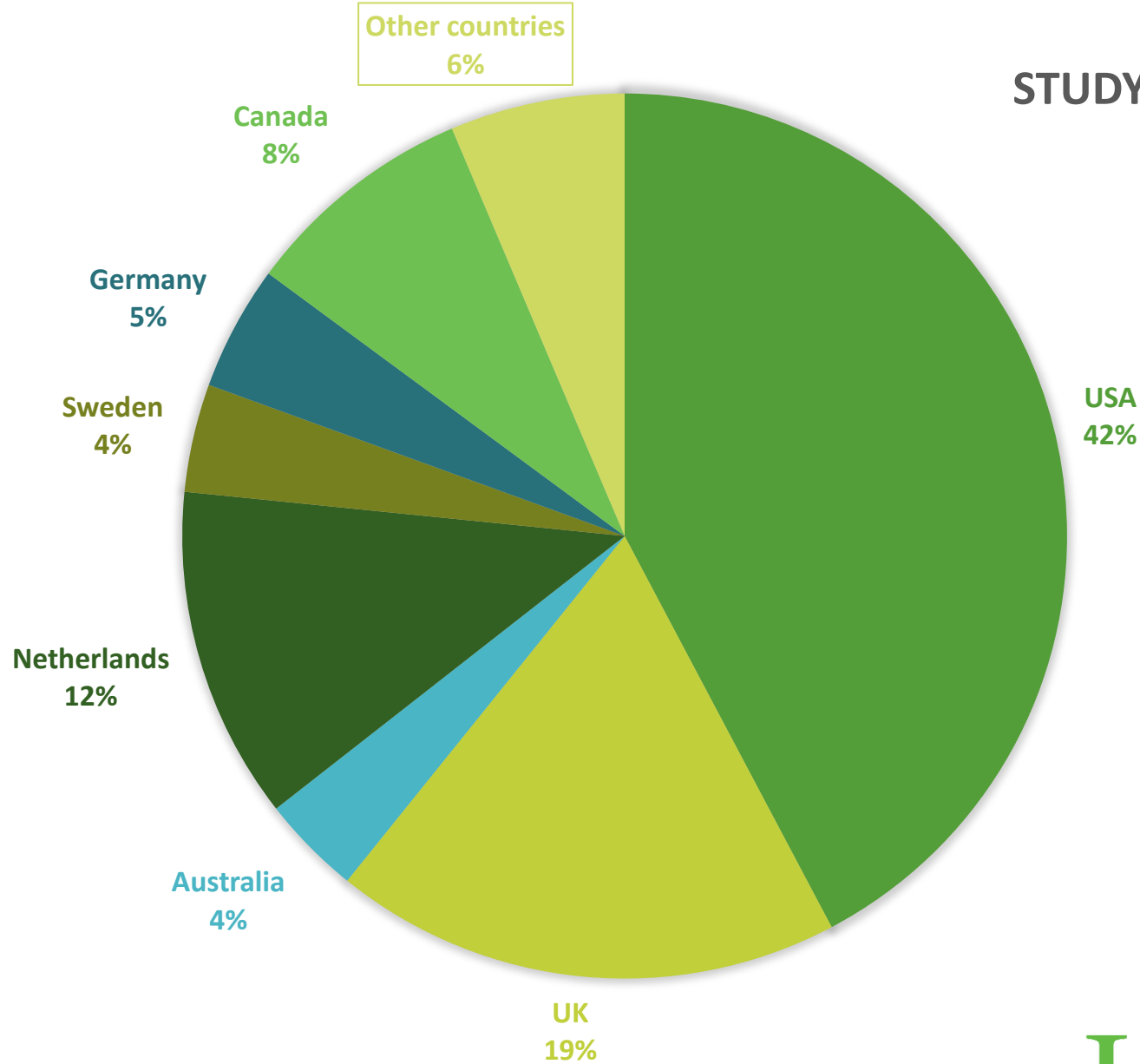
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Our questions

- What are the factors that affect quality of life in women with lipoedema?
- What are those psychological factors that we can impact to improve the quality of life of those with lipoedema?

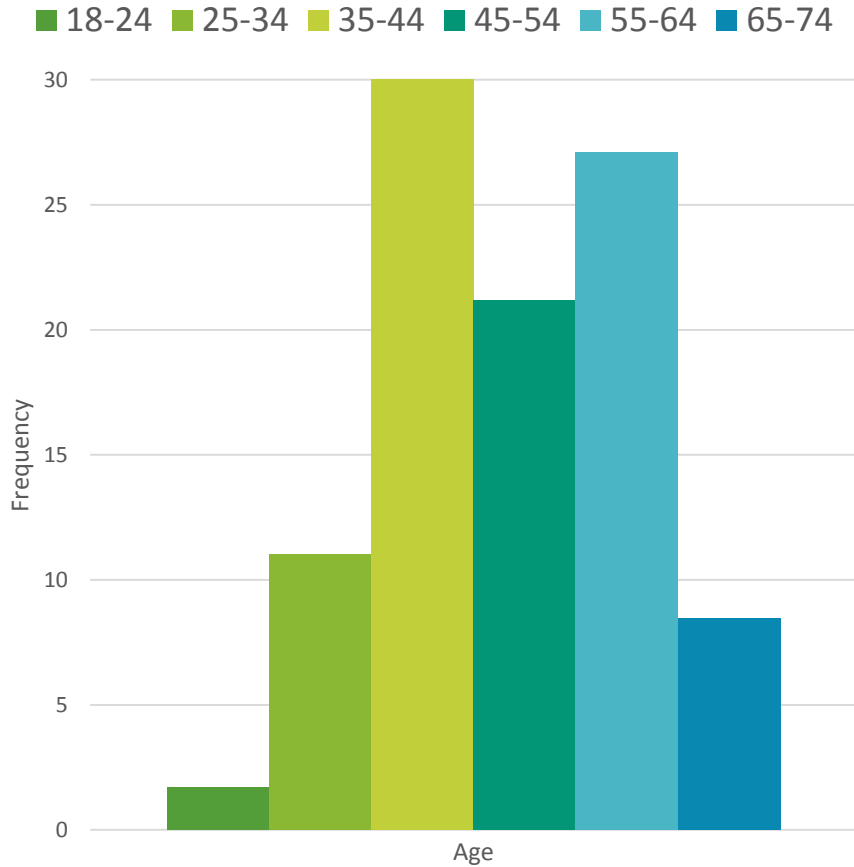
STUDY 2



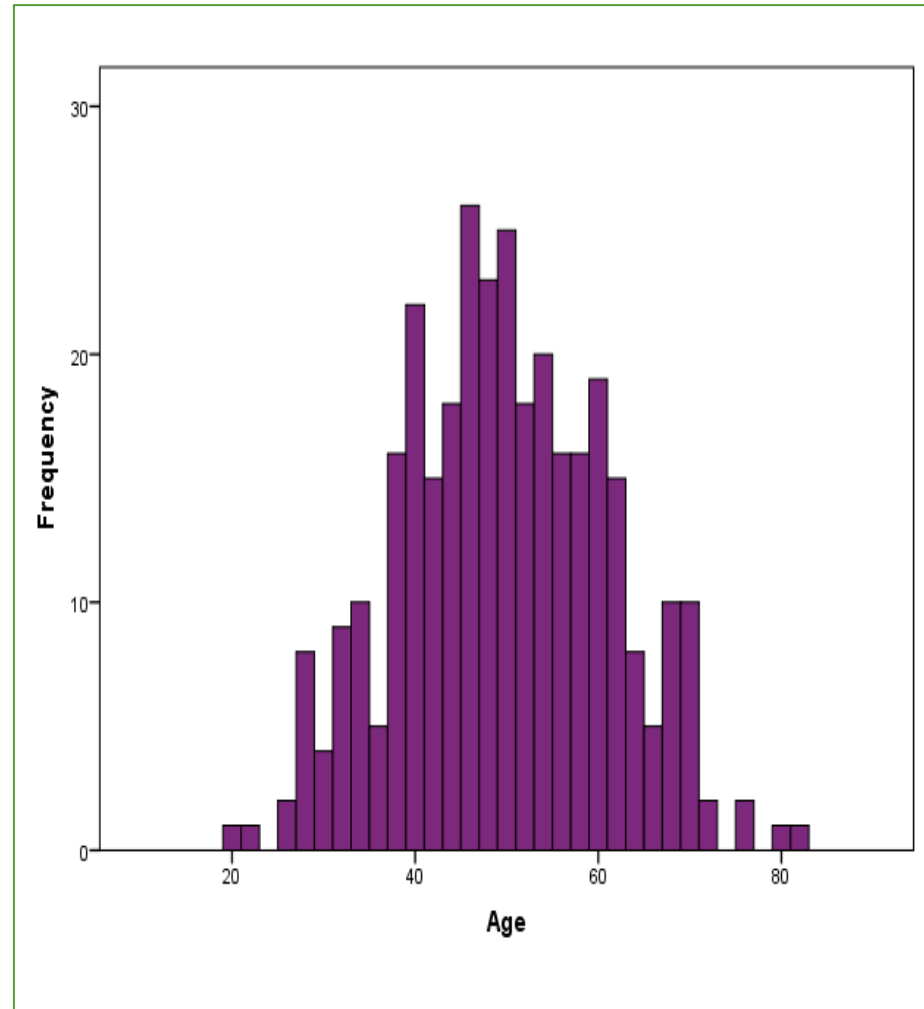
Dudek, J. E., Białaszek, W., Ostaszewski, P., & Smidt, T. (2018). Depression and appearance-related distress in functioning with lipedema. *Psychology, health & medicine*, 1-8.

Participants' Age

Study 1 N=118



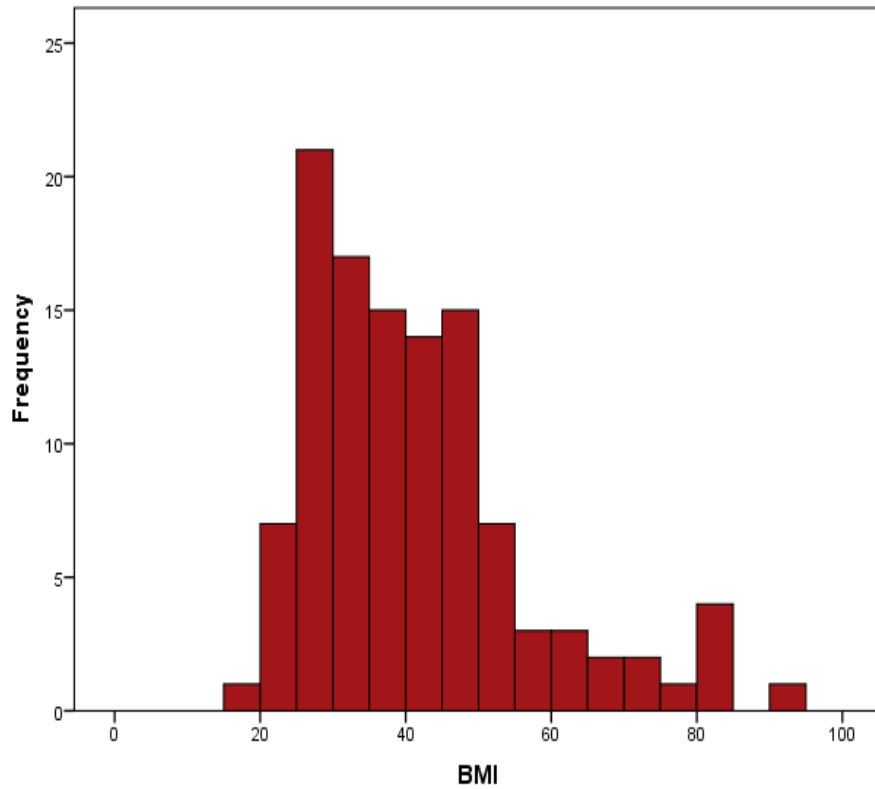
Study 2 N=328 M=49.18; SD=11.24



BMI (Body Mass Index)

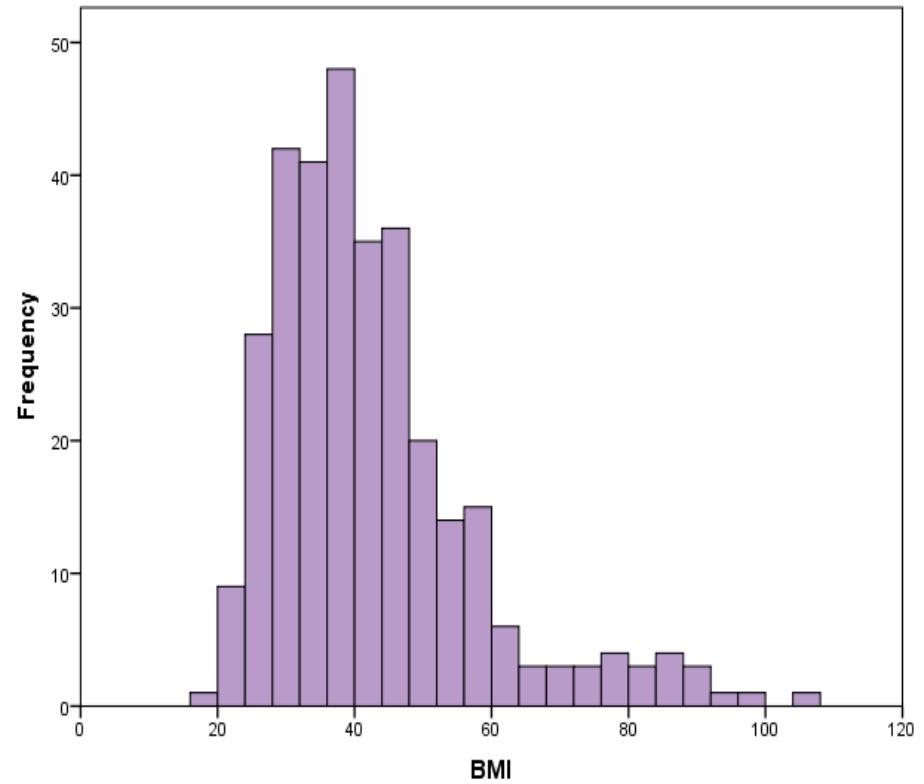
Study 1

M=41.24; SD=15.24 N=113



Study 2

M=42.51; SD=14.94 N=321



Lipoedema affects quality of life in all domains

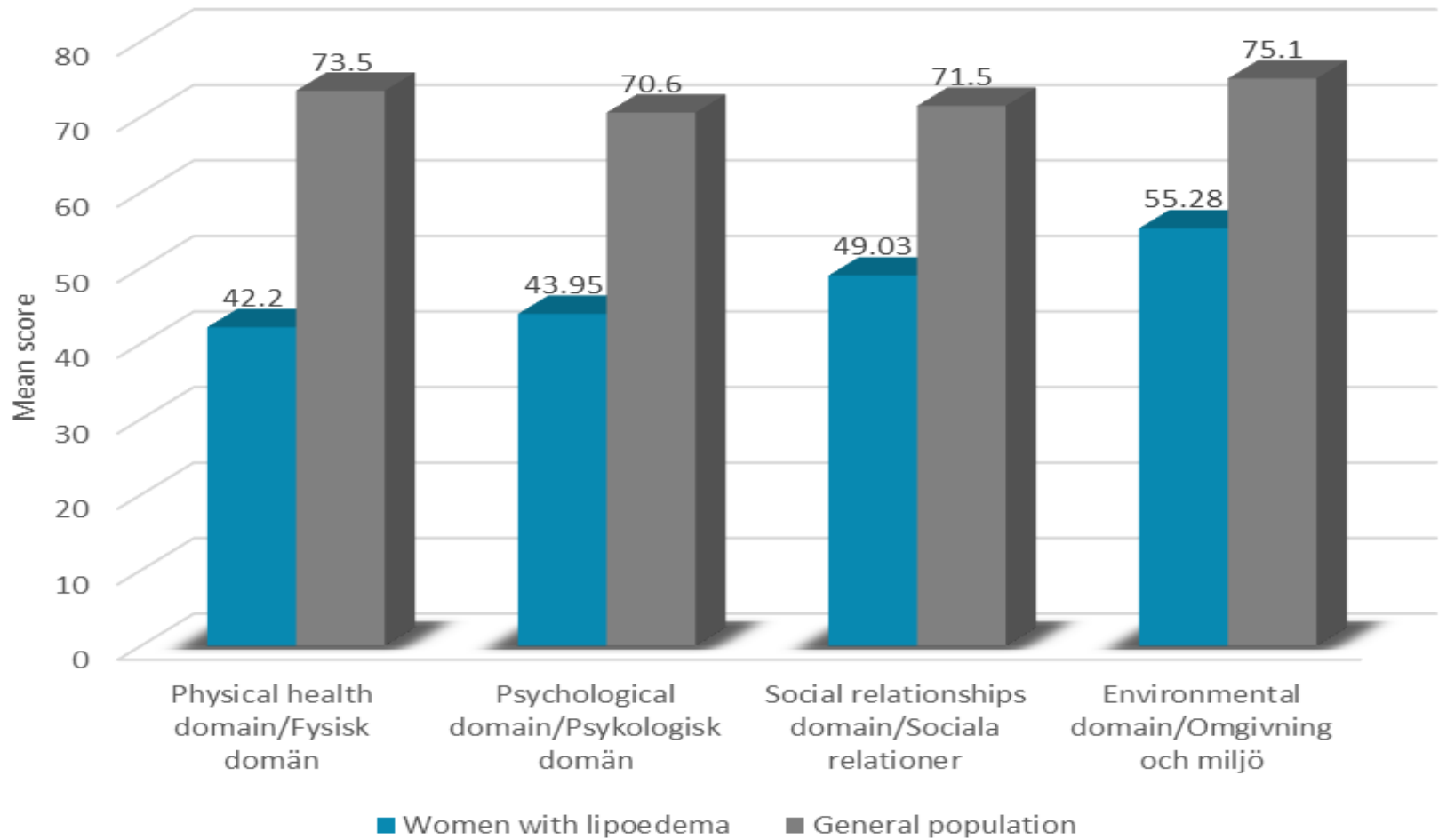
Physical
health

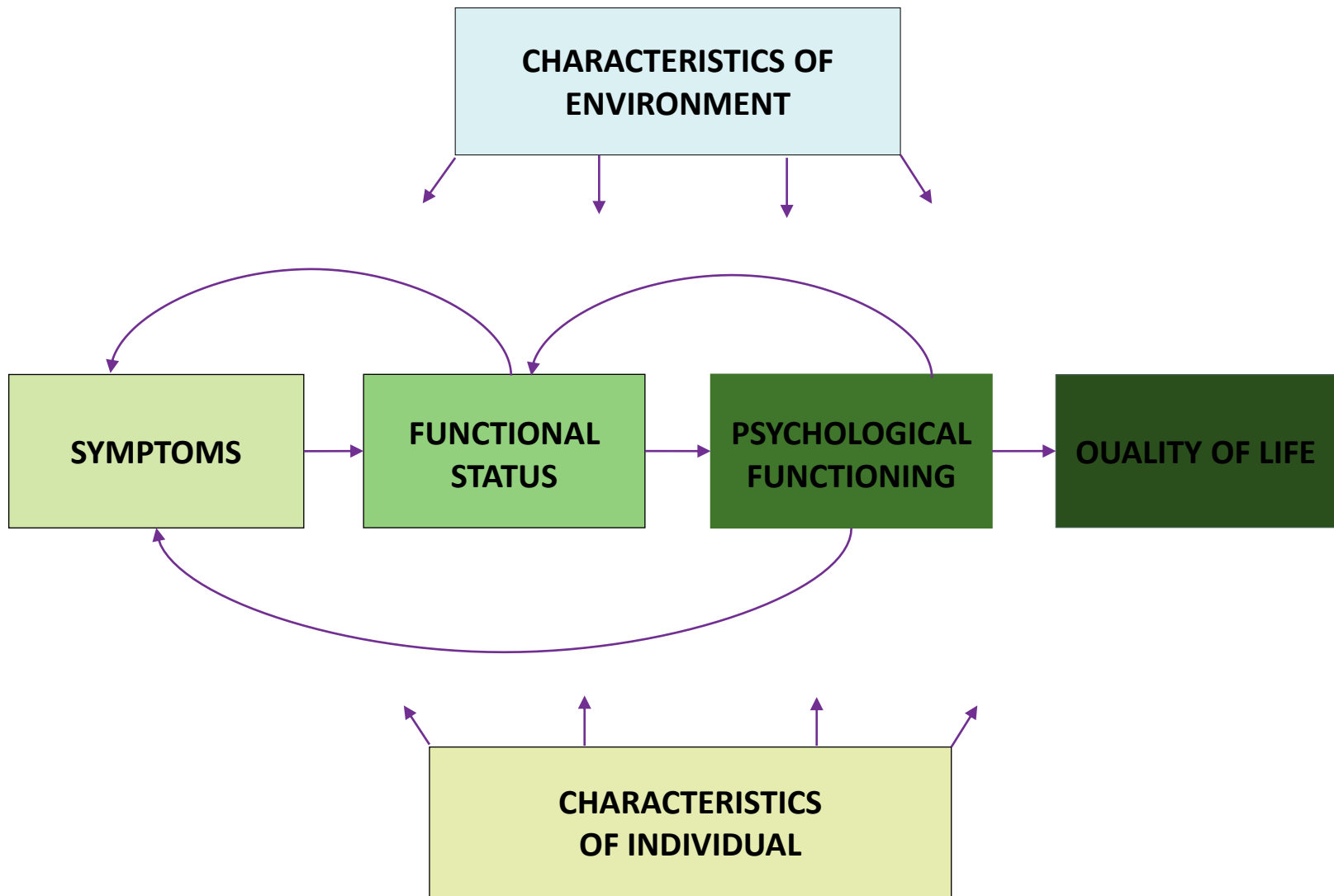
Psychological

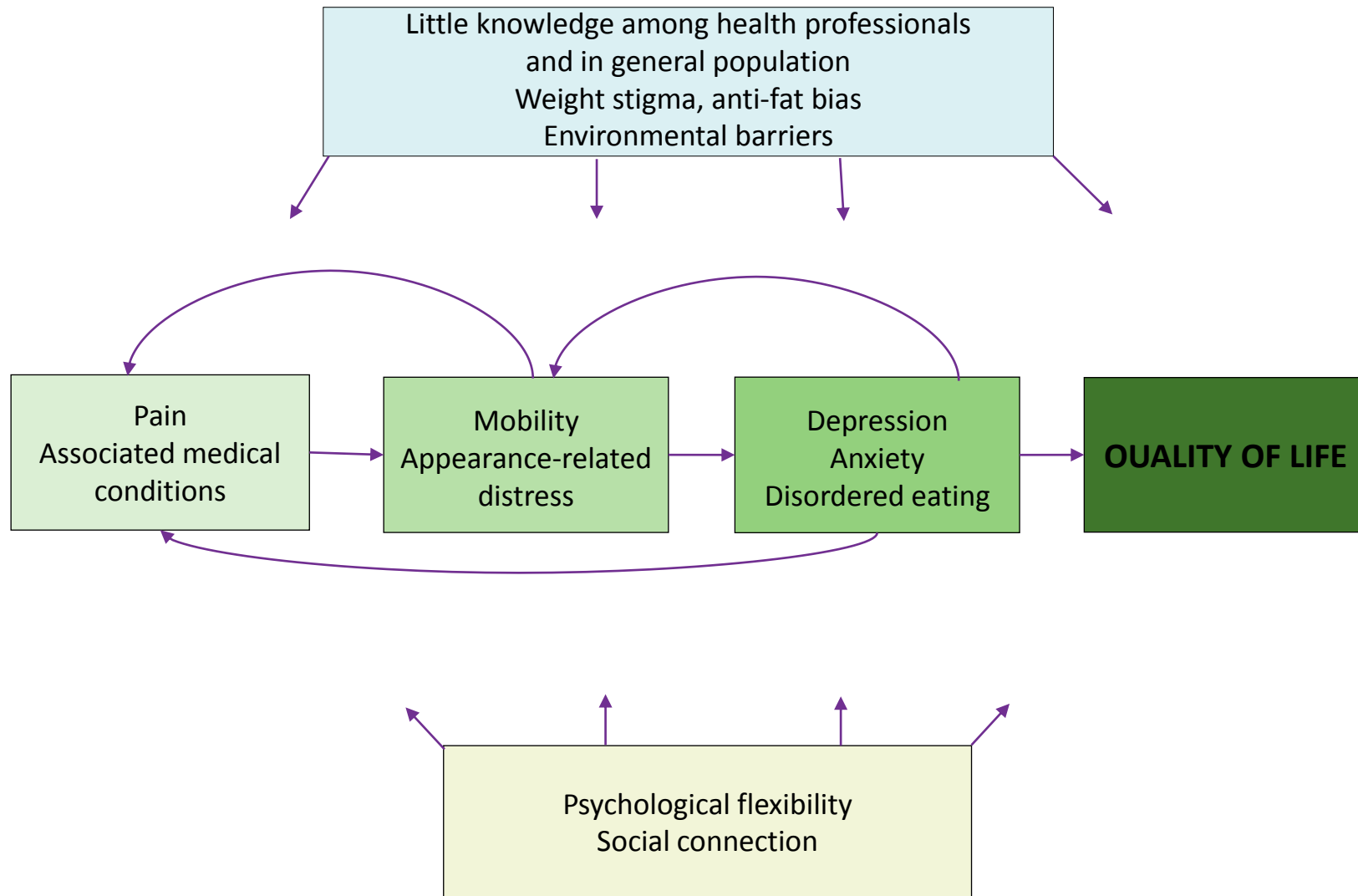
Social

Environmental

Quality of life in women with lipoedema and in general population
(WHOQOL-BREF, Transformed scores)
Livskvalitet hos kvinnor med lipödem och befolkningen i
allmänhet







Lipedema is little known

[Plast Reconstr Surg Glob Open](#). 2016 Sep; 4(9): e1043.
Published online 2016 Sep 28. doi: [10.1097/GOX.0000000000001043](https://doi.org/10.1097/GOX.0000000000001043)

PMCID: PMC5055019
PMID: [27757353](https://pubmed.ncbi.nlm.nih.gov/27757353/)

Lipedema: A Relatively Common Disease with Extremely Common Misconceptions

[Donald W. Buck, II, MD^{M*}](#) and [Karen L. Herbst, MD, PhD[†]](#)

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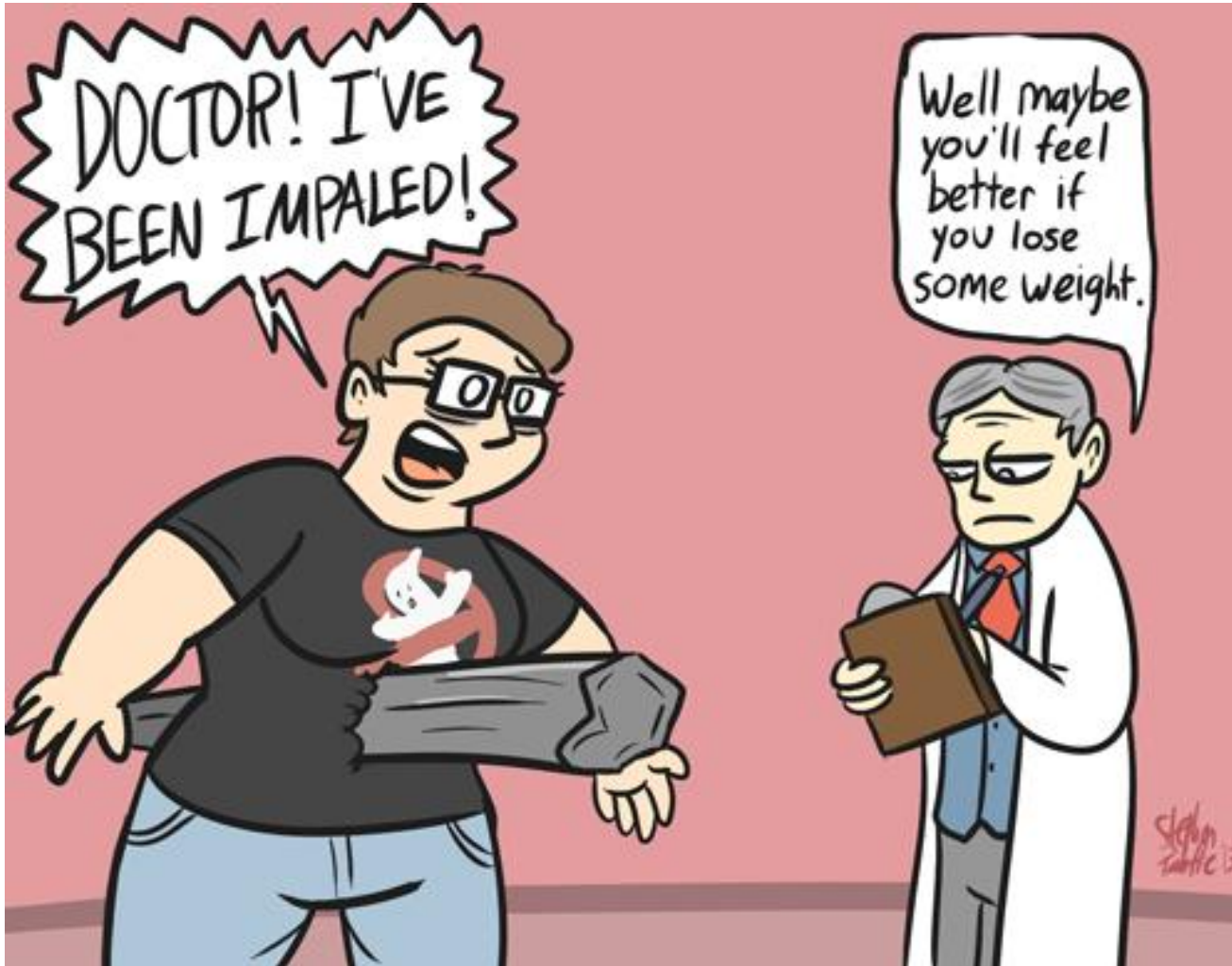
This article has been [cited by](#) other articles in PMC.

Abstract

Go to:


Lipedema, or adiposis dolorosa, is a common adipose tissue disorder that is believed to affect nearly 11% of adult women worldwide. It is characterized most commonly by disproportionate adipocyte hypertrophy of the lower extremities, significant tenderness to palpation, and a failure to respond to extreme weight loss modalities. Women with lipedema report a rapid growth of the lipedema subcutaneous adipose tissue in the

Weight stigma is prevalent



Women with lipedema encounter various environmental barriers

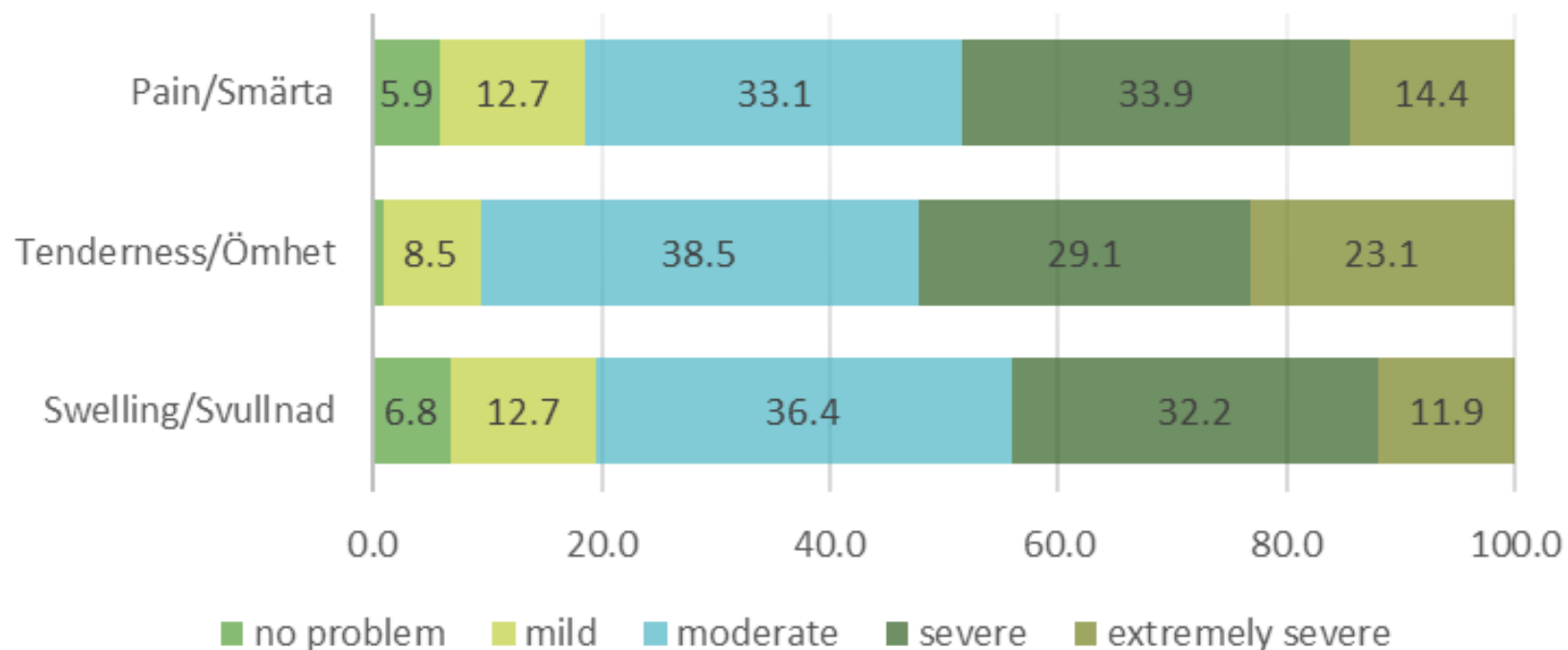




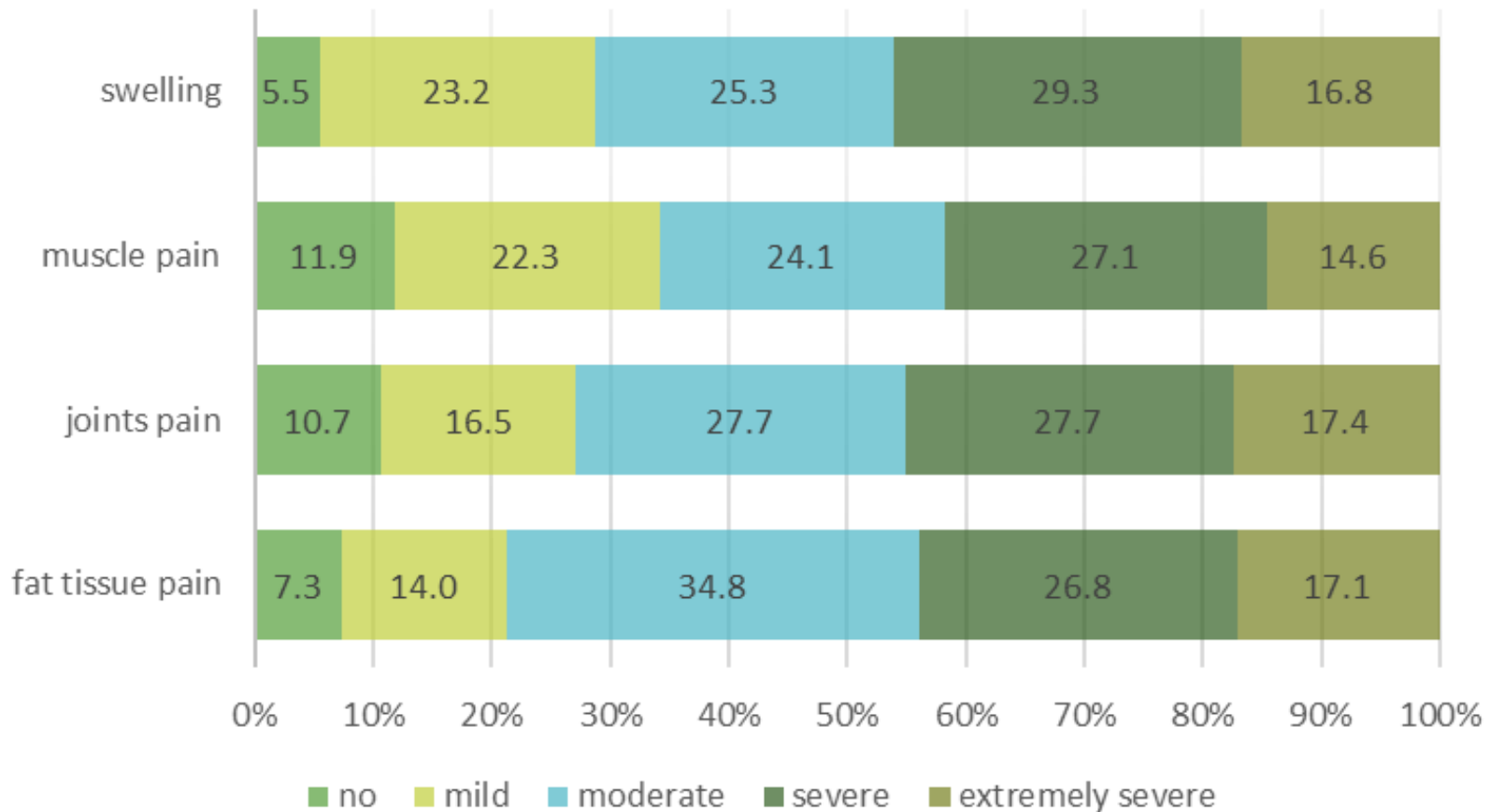
Lipoedema Symptom Severity

Pain

SYMPTOM SEVERITY/SYMPTOM SVÅRIGHETSGRAD (STUDY 1)



SYMPTOM SEVERITY (STUDY 2)



Chronic pain from psychological perspective

- „Pain is an unpleasant sensory and emotional experience associated with actual or potential tissue damage or described in terms of such damage” (International Association for the Study of Pain, 1994)
- Importance of psychological factors
 - Gate Control Theory, proposes a neural ‘gate’ that can be opened or closed in varying degrees to modulate incoming pain signals before they reach the brain (Melzack, Wall, 1965)

Psychological factors that may affect pain perception

Increased pain perception

- Anxiety, worry, tension, depression
- Pain avoidance
- Boredom (little involvement in daily activities)
- Loneliness

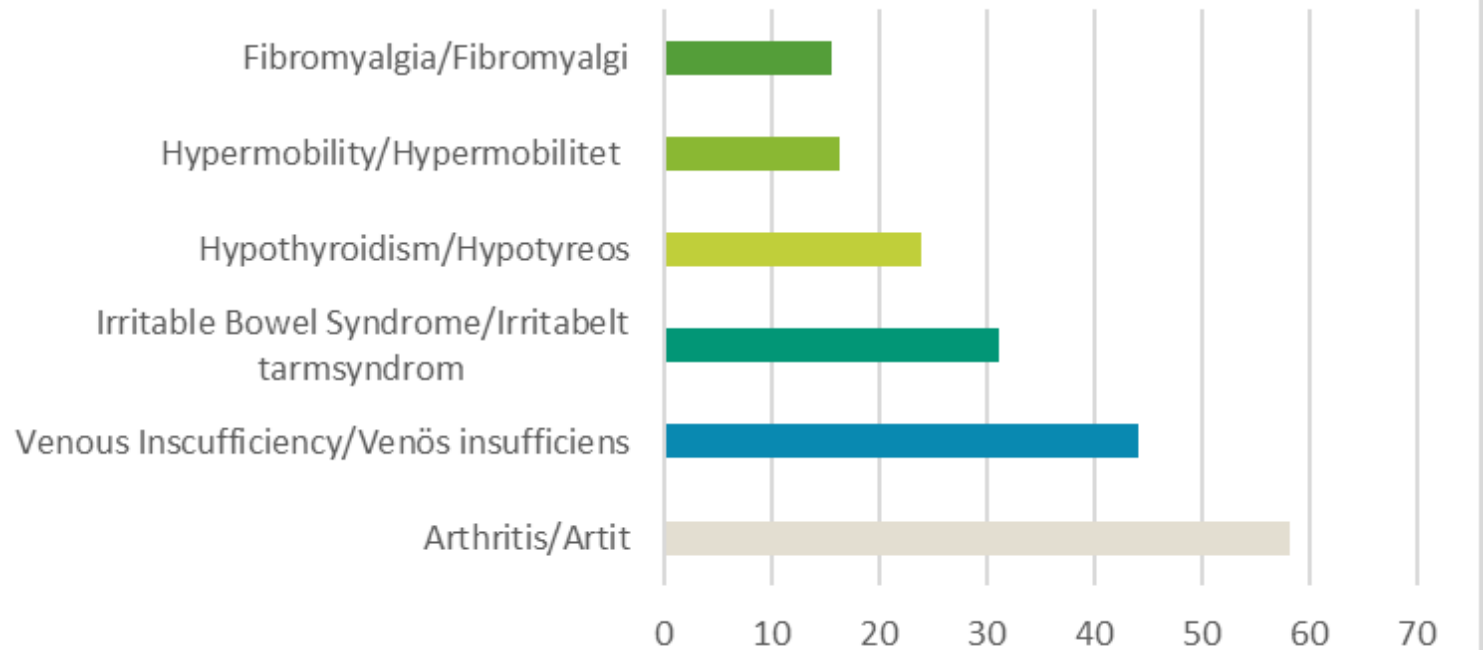
Lower pain perception

- Gratitude, joy, fulfillment, excitement
- Pain acceptance
- Involvement and interest in important life activities
- Companionship

How to cope with pain in lipoedema?

- Multidisciplinary approach - most effective
- Monitor your (your patient's) pain and various factors that may affect it : What is affecting your pain? When is it more severe? When is it less severe?

Associated medical conditions Associerade medicinska tillstånd(%)

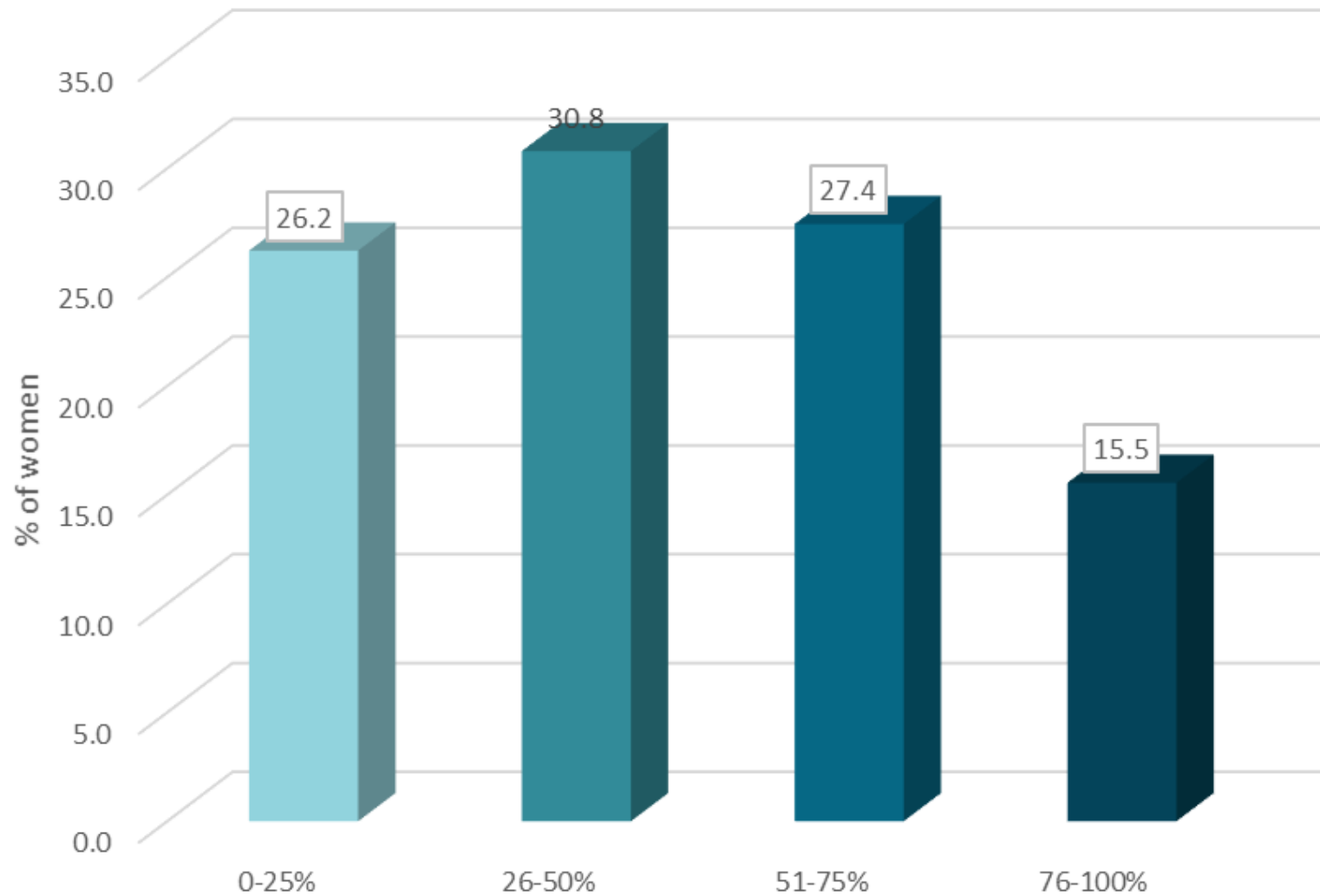


Associated medical conditions need further and more detailed investigation. They all may contribute to lower quality of life. Treatment needs to be individualized.

Mobility

person's ability to perform
everyday tasks: any of usual work,
housework or school activities,
usual hobbies, recreational or
sporting activities

Maximal Function of Lower Extremities (LEFS) (Study 2)



Binkley JM, Stratford PW, Lott SA, Riddle DL.(1999) The Lower Extremity Functional Scale (LEFS): scale development, measurement properties, and clinical application. North American Orthopaedic Rehabilitation Research Network. Phys Ther. 79(4):371-83.

Mobility

- Lowered perception of pain
- Lower risk of depression
- Lower likelihood of weight gain
- Lower risk for cardiovascular and respiratory disease
- Better overall health, and specifically brain health



Mobility from psychological perspective

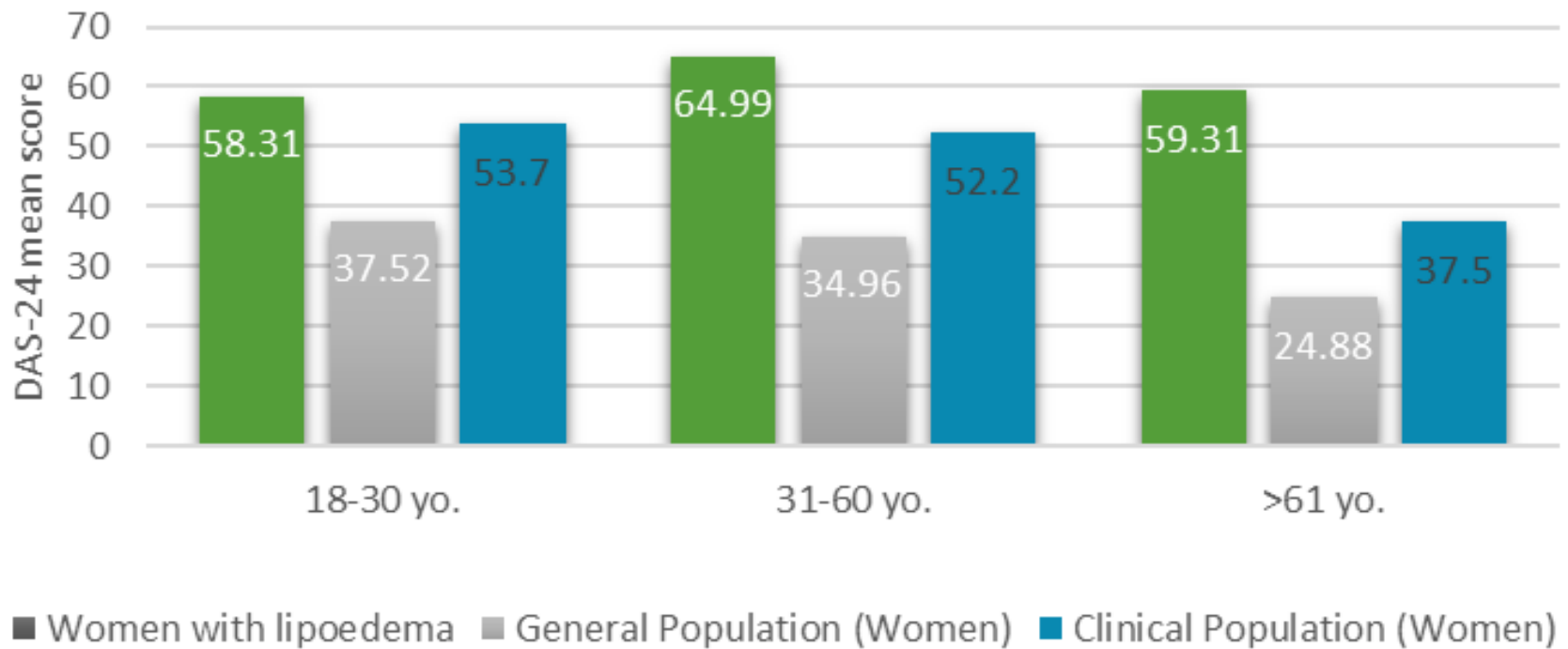
What are your barriers to be more physically active?

What are you patients barriers to be more physically active?

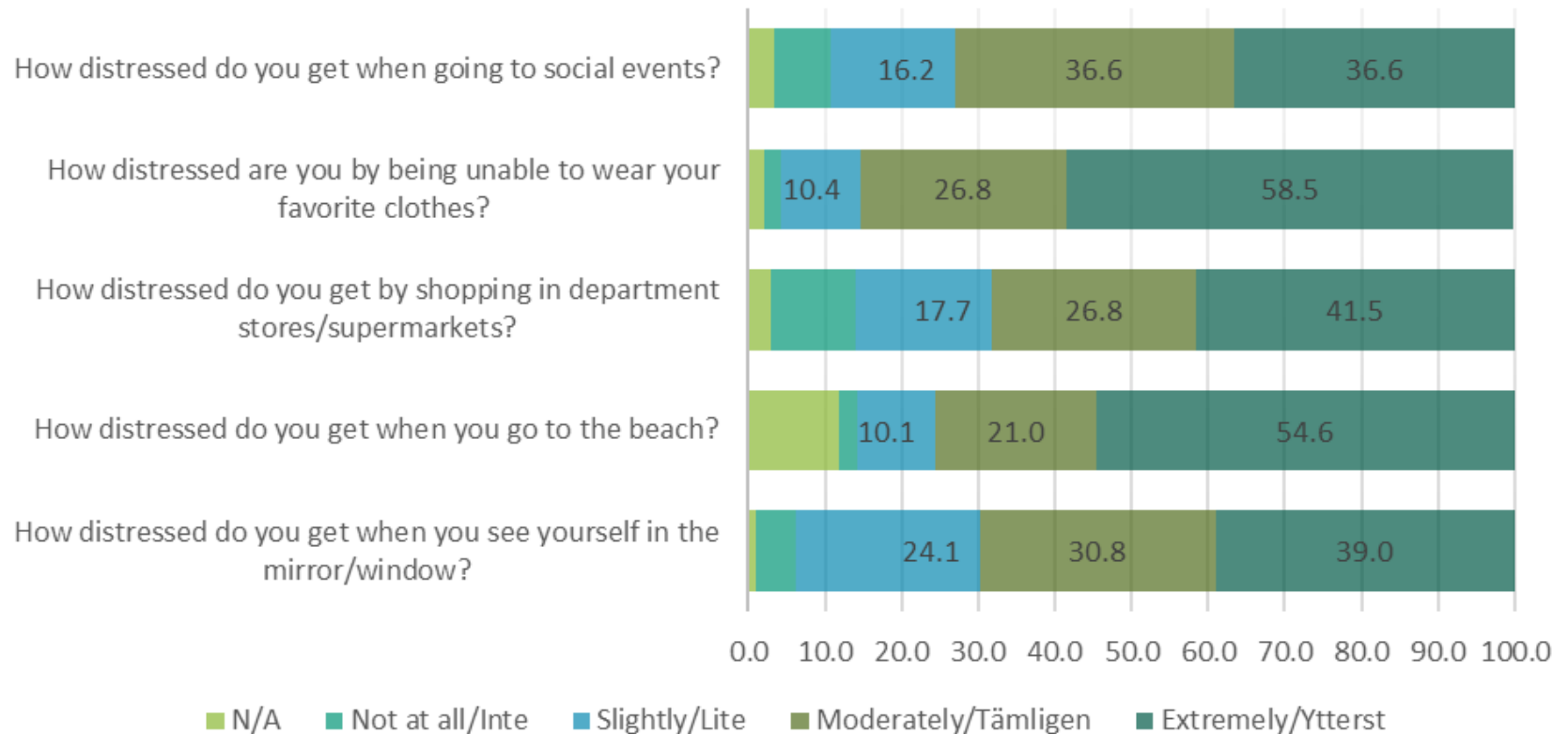
Appearance related distress

negative emotions of fear, social anxiety, shame, and negative affect along with a behavioral response of avoidance and withdrawal that frequently disrupts lifestyle

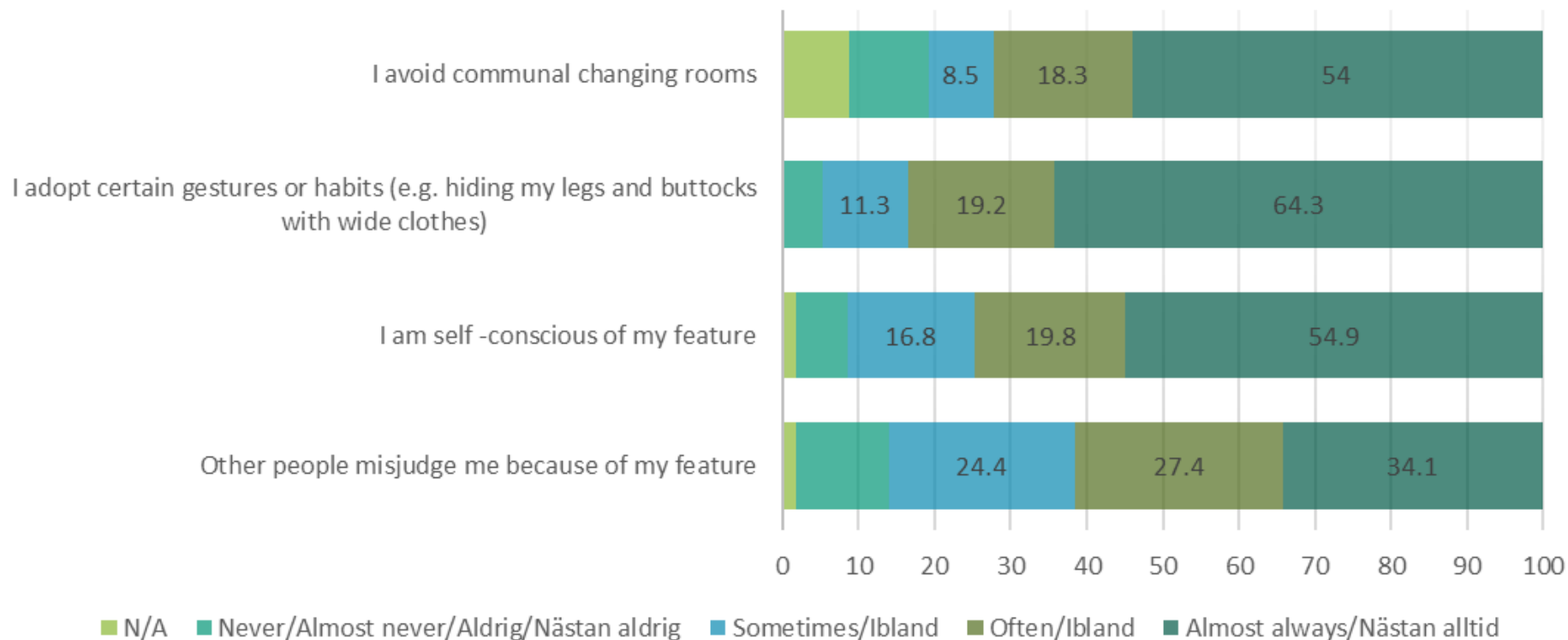
Appearance related distress Utseende relaterad stress (DAS-24) (Study 2)



EXAMPLE QUESTIONS EXEMPEL FRÅGOR DAS-24

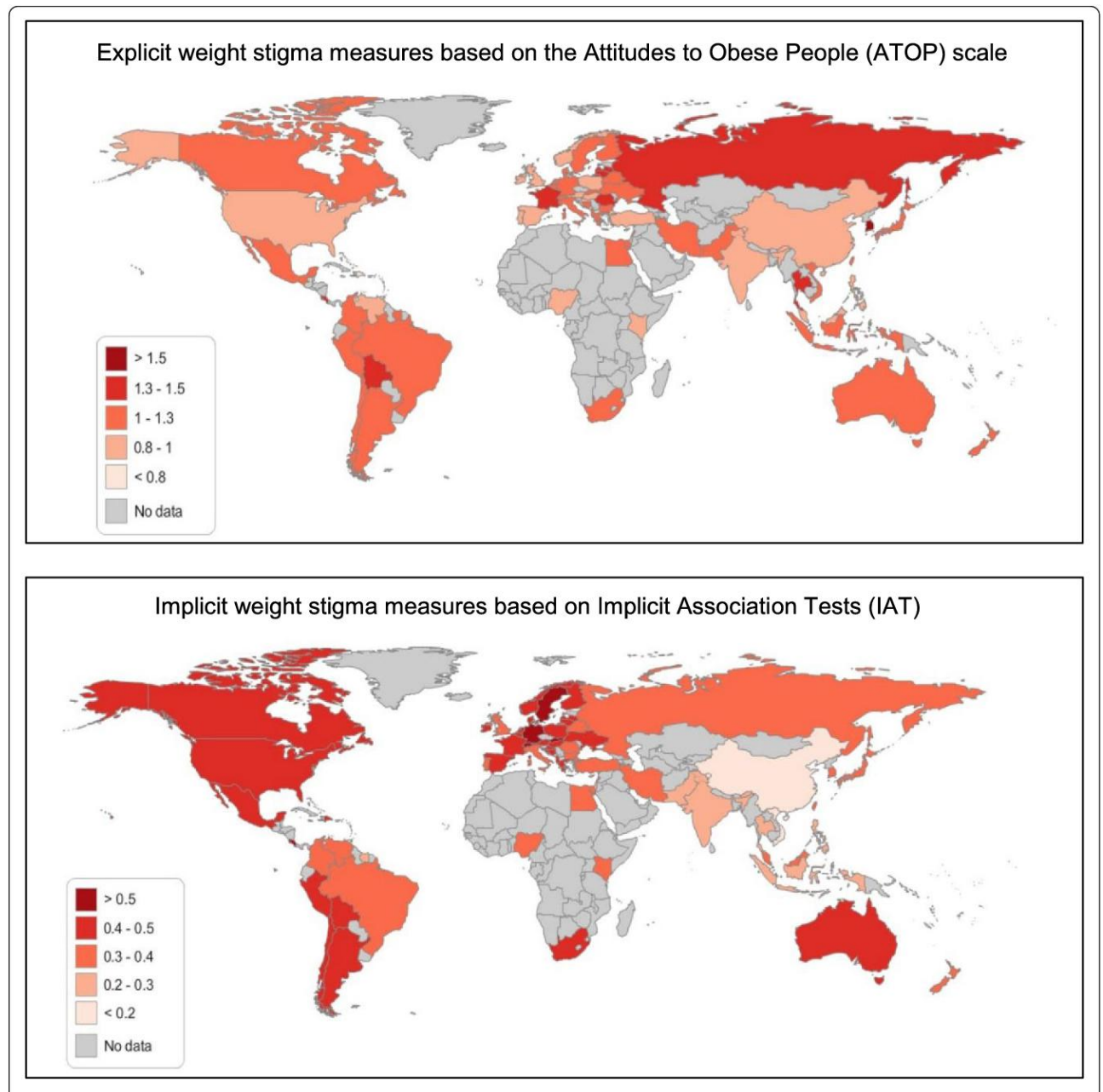


EXAMPLE QUESTIONS EXEMPEL FRÅGOR DAS-24



Carr, T., Moss, T., Harris, D. (2005). The DAS24: a short form of the Derriford Appearance Scale DAS59 to measure individual responses to living with problems of appearance. *British Journal of Health Psychology*, 10 (Pt 2), 285–298.
<http://doi.org/10.1348/135910705X27613>

Weight stigma is prevalent




Brewis, A., Sturtzsreetharan, C.L., & Wutich, A.Y. (2018). Obesity stigma as a globalizing health challenge. *Globalization and health*.

Weight stigma affects health


- Psychological disorders
- Lower physical activity
- Binge eating
- Increased calorie intake
- Physiological stress
- Weight gain

„Evidence collectively demonstrates negative implications of stigmatization for weight-related health correlates and behaviors ”




When do you experience
appearance-related
distress?

When is your patient
experiencing appearance-
related distress?



What would you do
differently if you were
proud of the way you look
like?

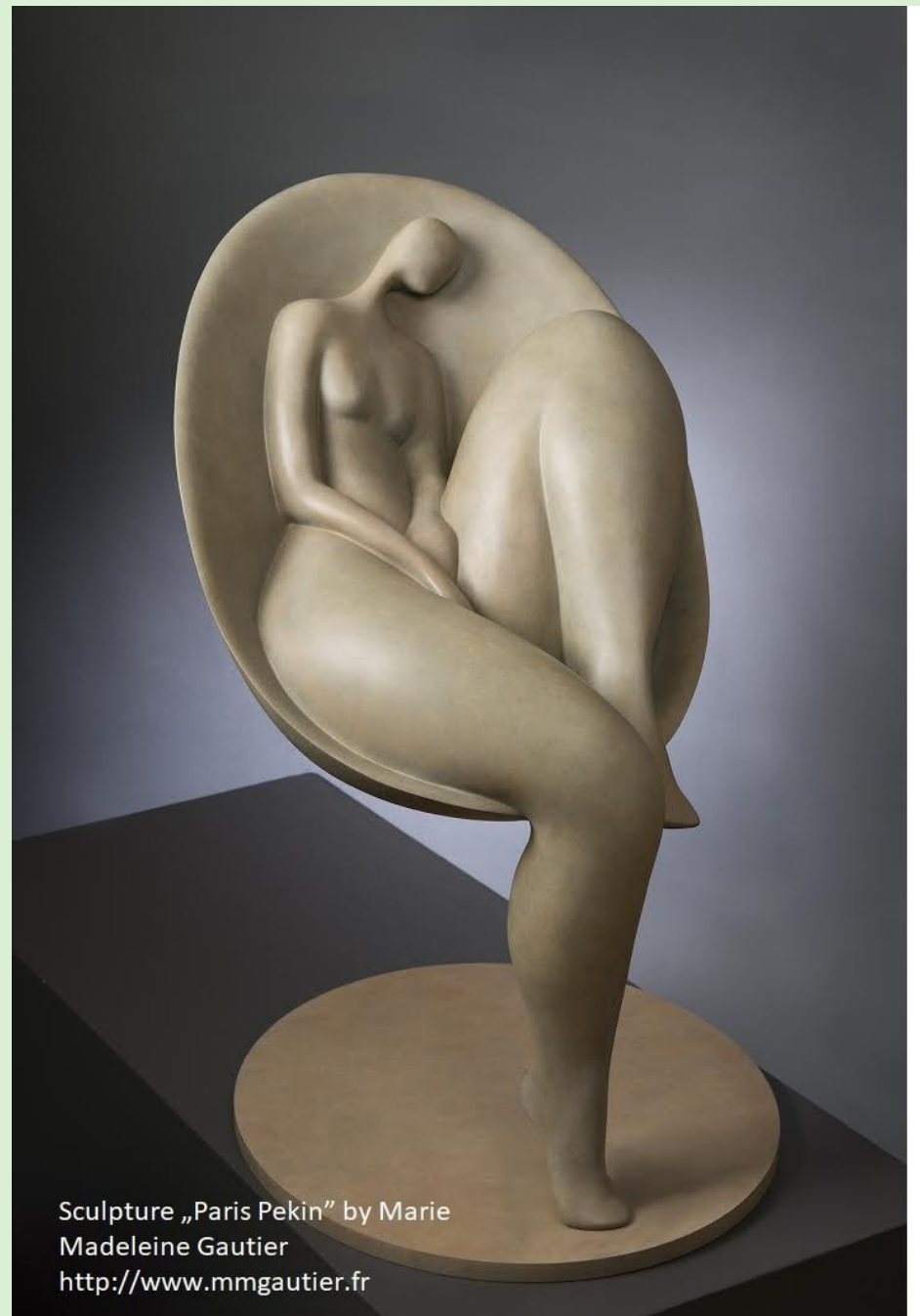
How the appearance
related distress is stopping
your patient?



Help yourself/ your
patient to cope with
appearance-related
distress and do what
matters now!

Appreciate
the Beauty
of Your Body

Alive
Breathing
Changing



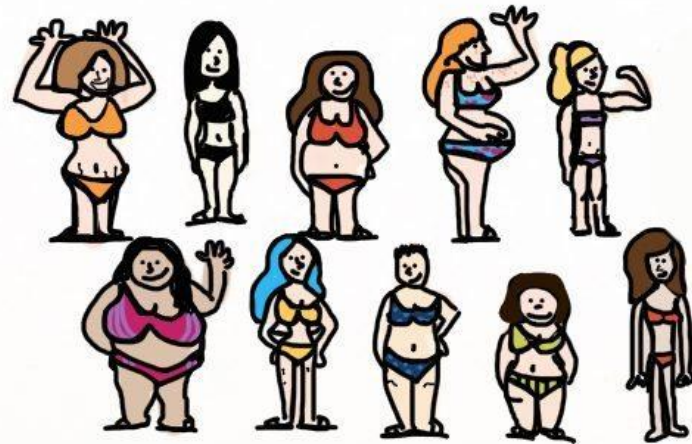
Sculpture „Paris Pekin“ by Marie
Madeleine Gautier
<http://www.mmgautier.fr>

Celebrate body diversity



Advocate for
body
diversity

HOW TO GET A BIKINI BODY?



@proteinpow

PUT A BIKINI ON YOUR BODY.

#EachBodysReady

Eating disorders

Overly restrictive dieting

Excessive focus on the appearance, food,
weight

Binge-eating episodes

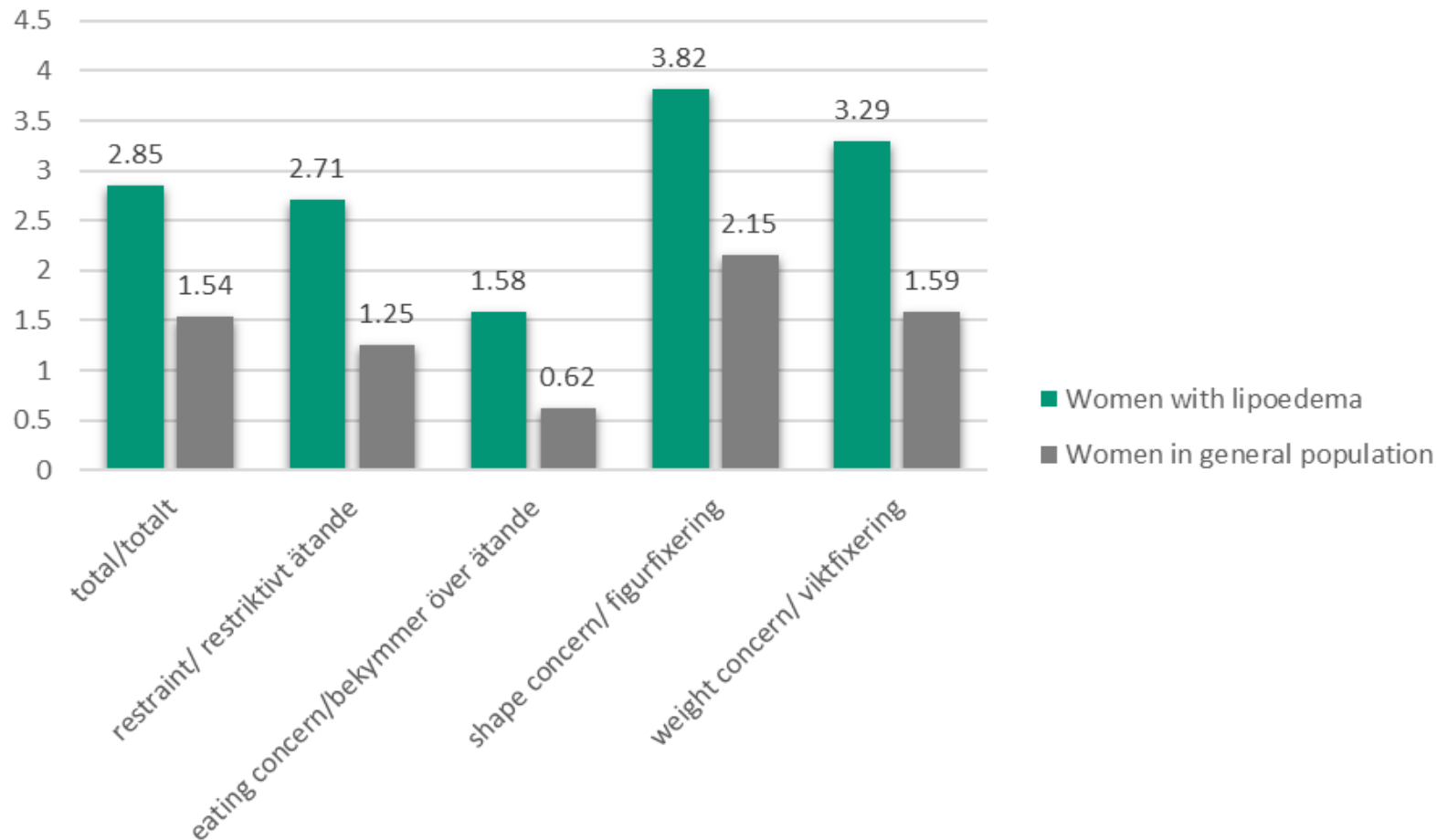
Purging after meals (compensatory
behaviors)

Shame related with eating

Self-evaluation based on shape/weight

EDE-Q (mean score) in women with lipoedema and in women in general population

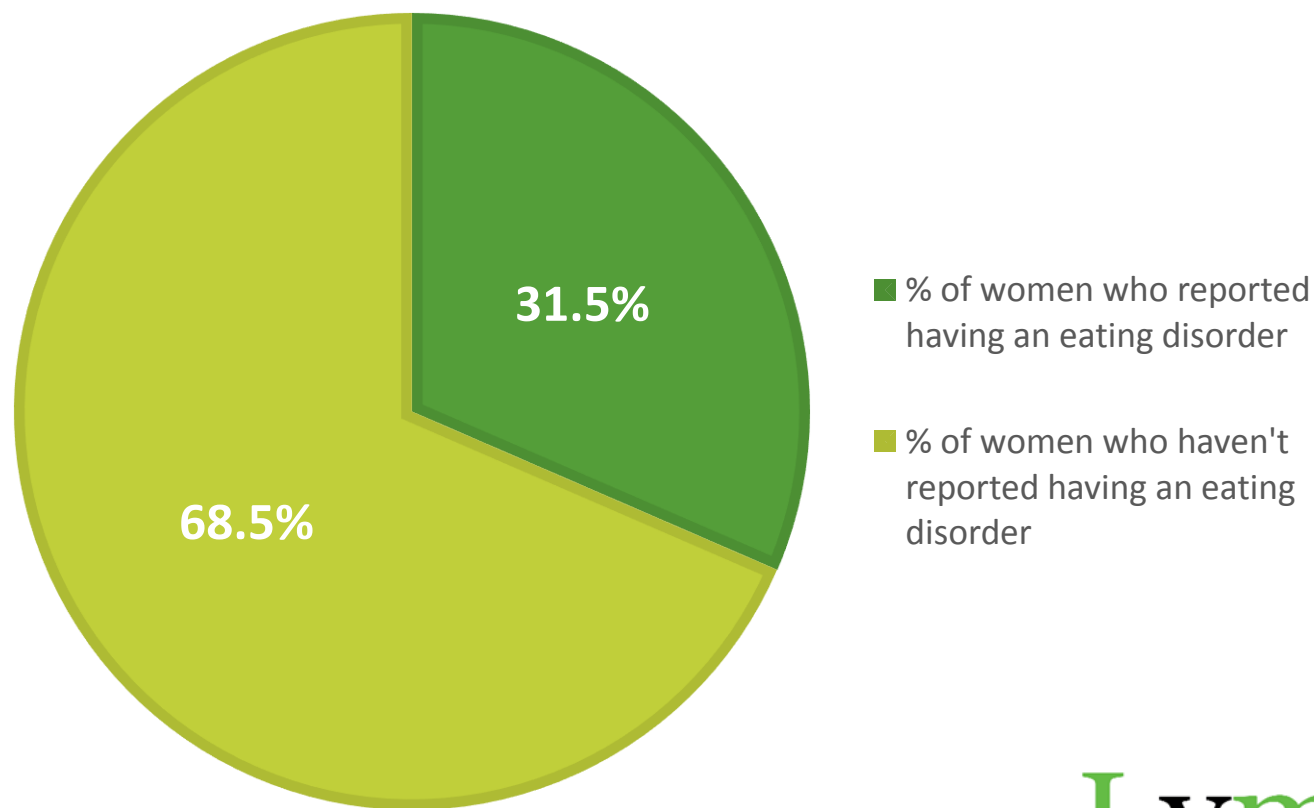
EDE-Q (medelvärde) hos kvinnor med lipödem och hos kvinnor i allmän befolkning (Study 1)



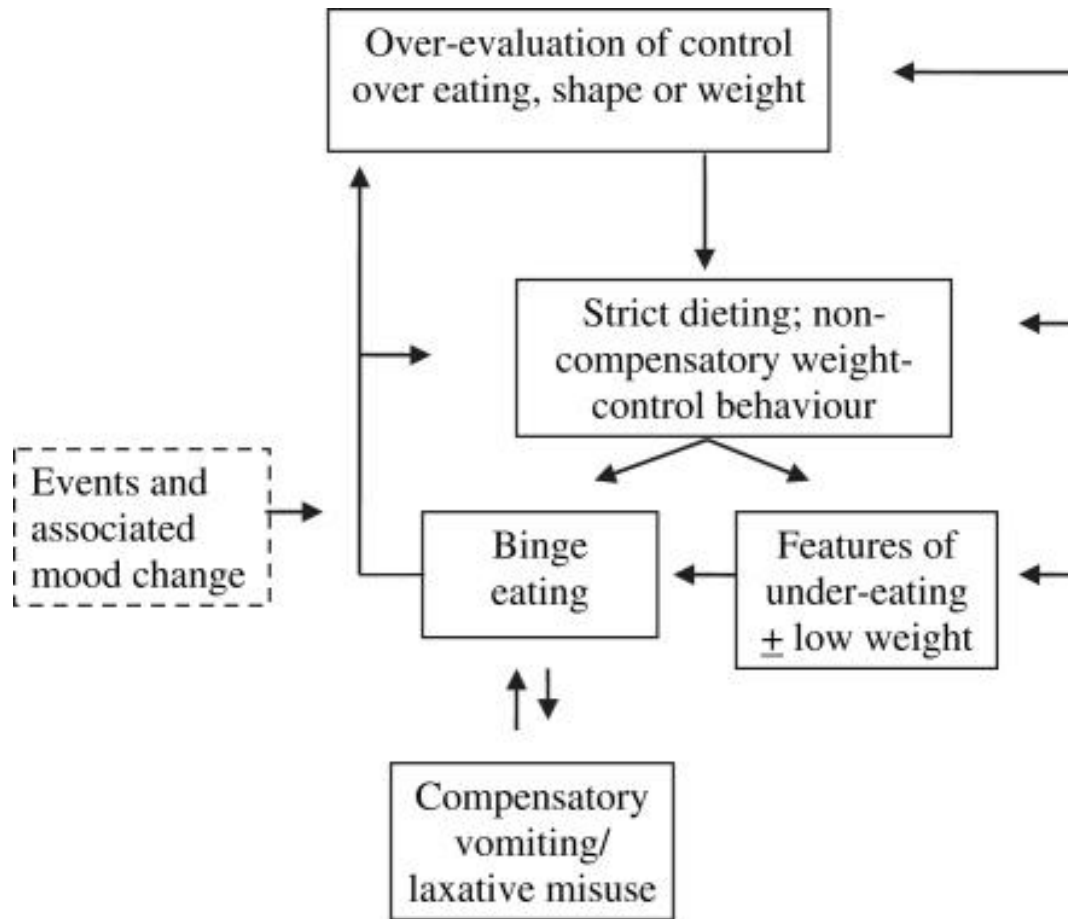
Self-reported eating disorders

Självrapporterad ätstörningar

(Study2)



Why women with lipoedema may be at risk of developing eating disorders?



Transdiagnostic
cognitive-
behavioral
perspective on
eating disorders

WHAT WOULD BE YOUR WAY OF EATING?

- What would support the way YOU want to live?
- What suits your HEALTH, has good LONGTERM consequences?
- What allows you to ENJOY your life?
- It is your MINDFUL CHOICE
- Process of choosing



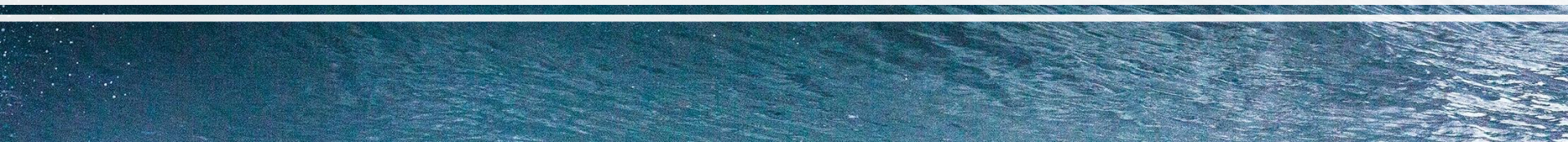
Be aware of moments of choice



Choose wisely

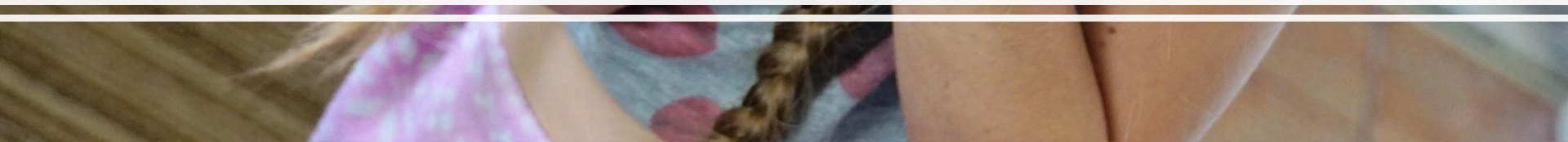


Surf the wave of discomfort





And enjoy!





Anxiety and depression

GENERALIZED ANXIETY DISORDER GENERALISERAT ÅNGESTSYNDROM (GAD-7)(STUDY 2)

■ no symptoms/inga symtom ■ mild ångest ■ moderate /medel ångest ■ severe/allvarlig ångest

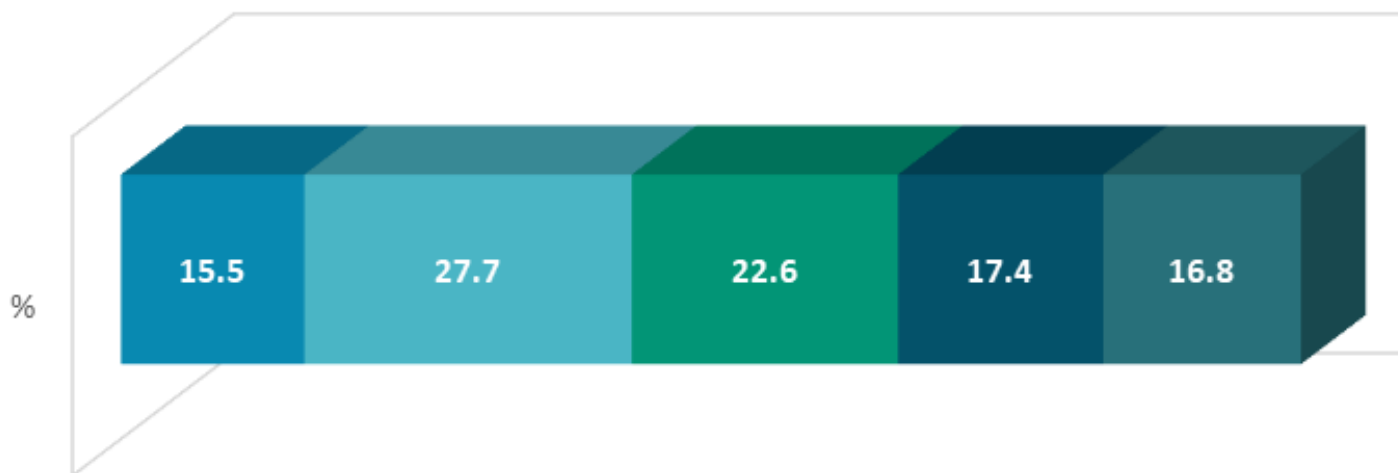


Spitzer, R. L., Kroenke, K., Williams, J. B., & Löwe, B. (2006).

A brief measure for assessing generalized anxiety disorder: the GAD-7. *Archives of internal medicine*, 166(10), 1092-1097.

DEPRESSION SEVERITY DEPRESSION SVÅRIGHETSGRAD (PHQ-9) (STUDY 2)

■ no/ingen ■ mild ■ moderate/måttlig ■ moderately severe/medelsvår ■ severe/svår

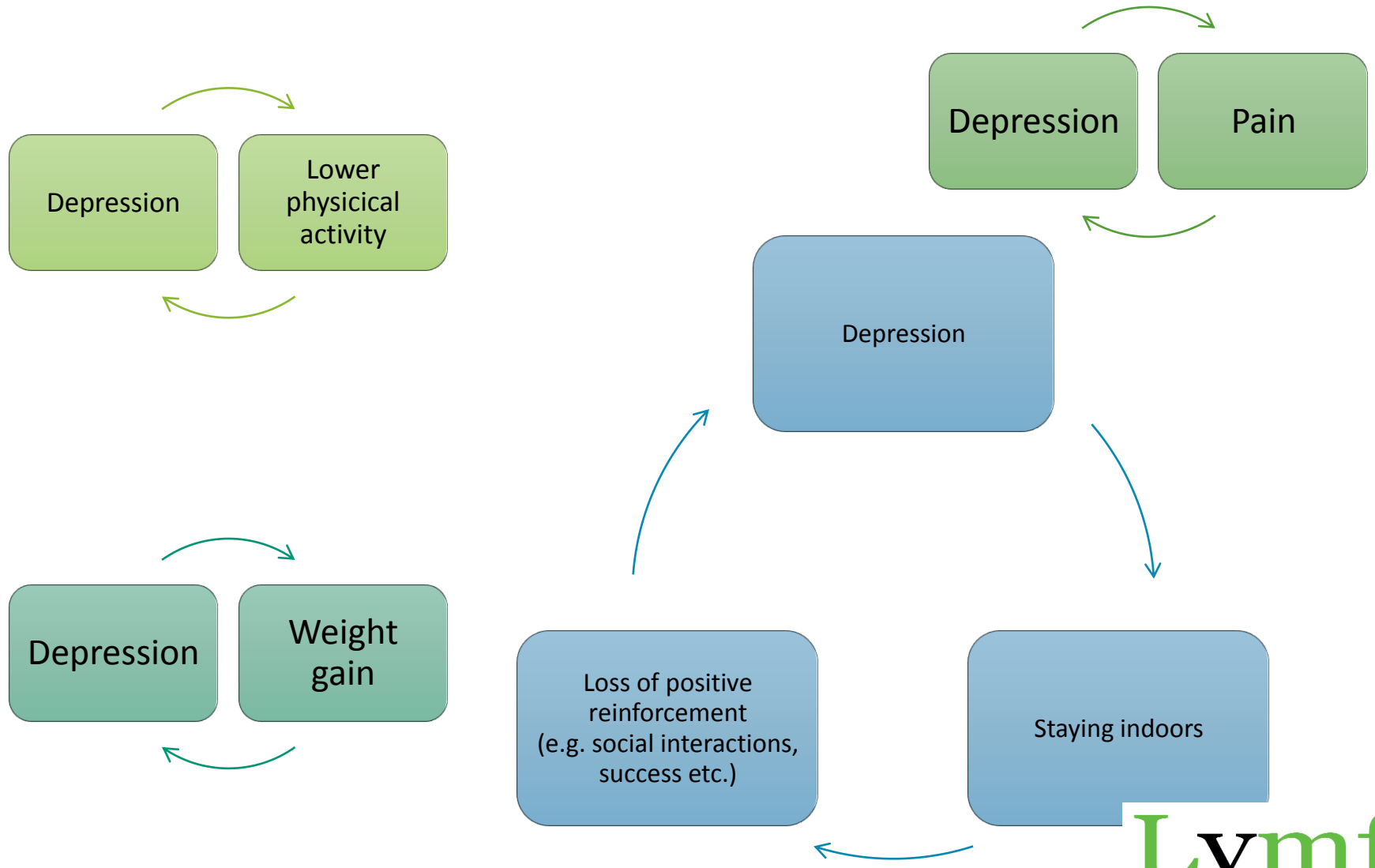


Why women with lipoedema are at risk for depression?

- Difficulty in controlling the disease
- Restrictive dieting, malnutrition
- Pain
- Lack of physical activity, immobility
- Loneliness
- Experiences of fat shaming, weight stigmatization
- Neuroinflammation

Walker, A. K., Kavelaars, A., Heijnen, C. J., & Dantzer, R. (2014). Neuroinflammation and comorbidity of pain and depression. *Pharmacological reviews*, 66(1), 80-101.

Visious circles of depression



Psychological aspects of functioning in women with lipoedema need to be included in multidisciplinary approach to treatment.

Individual factors

ACT and connect
to live better with
lipoedema

ACT (Be psychologically flexible) (psykologisk fleksibilitet)

Accept



Choose



Take
action



Psychological flexibility mediates the change in various health related problems

- chronic pain,
- fibromyalgia,
- stigmatization,
- depression,
- anxiety,
- weight management,
- body dissatisfaction,
- physical activity,
- disordered eating

Psychological
flexibility was
related to:

- Better quality of life,
- Lower level of depression and anxiety
- Lower level of appearance related distress
- Higher level of mobility and lower symptom severity

Focus on what you can control and accept what is beyond your control

Live meaningful life now, don't postpone your life for later

When you move towards what matters, you may encounter pain or discomfort

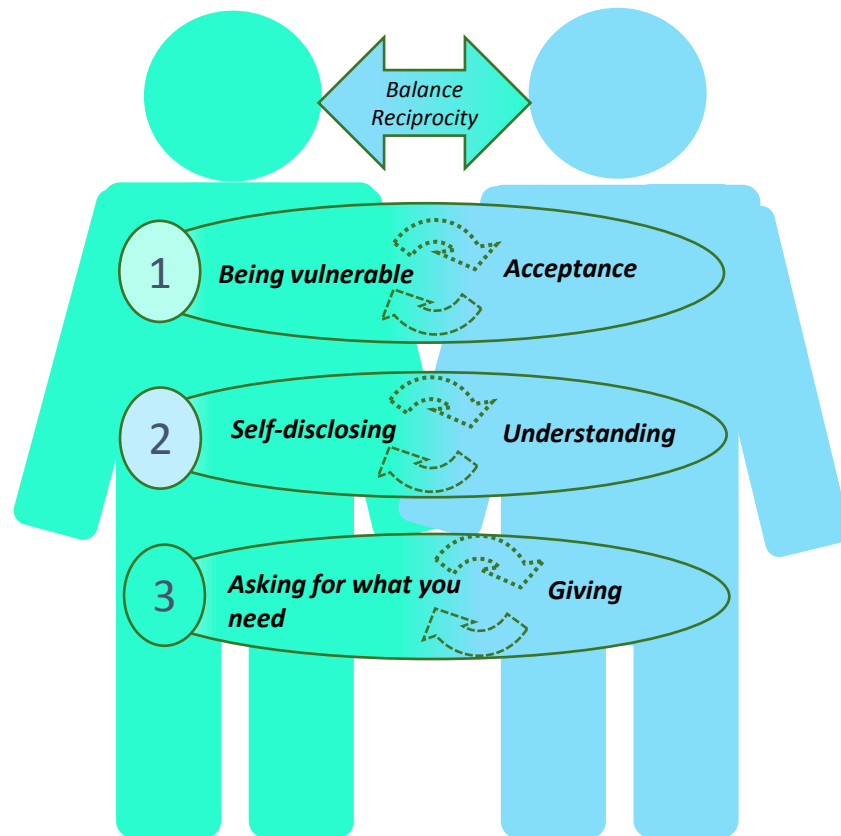
Engage in important activities even in the presence of pain or discomfort

If needed re-formulate your goals

Take care of your own health as you would take care about your loved one

Be psychologically flexible (ACT)

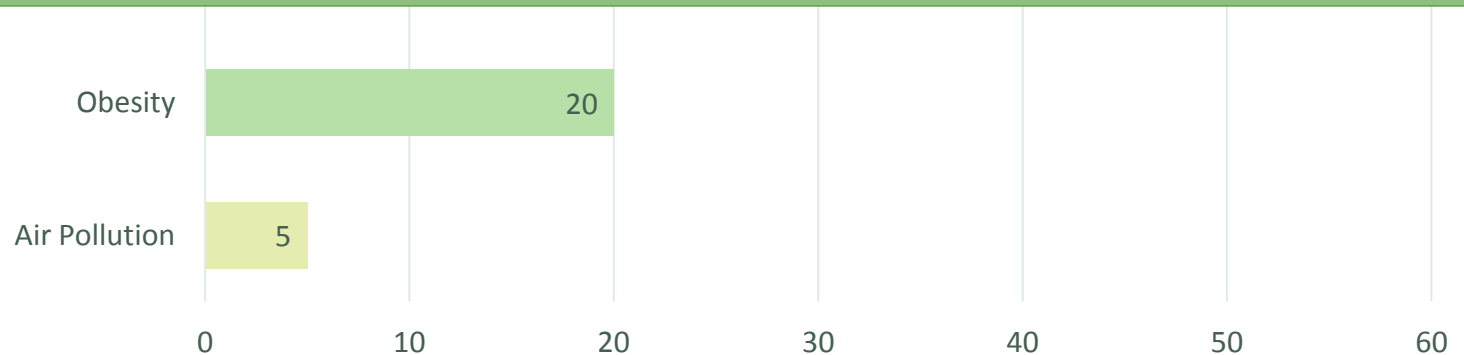
CONNECT (Social Connection)



Haworth, K., Kanter, J. W., Tsai, M., Kuczynski, A. M., Rae, J. R., & Kohlenberg, R. J. (2015). Reinforcement matters: A preliminary, laboratory-based component-process analysis of Functional Analytic Psychotherapy's model of social connection. *Journal of contextual behavioral science*, 4(4), 281-291.

Increase in odds of mortality due to various public health conditions

Loneliness has serious consequences to our longevity, health and well being



Holt-Lunstad J, Smith TB, Layton JB (2010) Social Relationships and Mortality Risk: A Meta-analytic Review. PLoS Med 7(7): e1000316. doi:10.1371/journal.pmed.1000316

Hostility and wound healing

Step 1



Step 2



Step 3

YEAR		MONTH				
MONDAY	TUESDAY	WEDNESDAY	THURSDAY	FRIDAY	SATURDAY	SUNDAY
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www.free-printable-calendar.net

- Lab “conflict interaction”
- Classified as “high conflict” or “low conflict”
- Each participant given “suction blister” wound
- Measure number of days for full healing of wounds

Number of Days for Full Healing to Occur (and this one)

8
7

Conclusion:

Good relationships may promote faster healing and physical health.

0

High conflict couples

Low conflict couples

Social
connection
was related
to:

- Better quality of life,
- Lower level of depression
- Lower level of appearance related distress
- Lower symptoms severity

Maintain relationships with people that you can rely on

Speak your truth

Listen empathetically

Take perspectives

Express your needs

Respond the needs of the other

Connect

Try it at the conference: ask someone and share

- For what in your life do you feel most grateful?
- If you could change anything about the way you were raised, what would it be?
- What is your biggest dream?
- What do you value most in a friendship?
- What is your most treasured memory?
- If you knew that in one year you would die suddenly, would you change anything about the way you are now living? How?

Conclusions for health professionals

Symptom severity (pain!), mobility, appearance-related distress, psychological functioning (depression, eating disorders) are important factors affecting quality of life in women with lipoedema

Psychological functioning should be assessed and patients at risk should get support that they need.

Conclusions for families and friends

Try to listen to and understand
your loved one

Don't minimize her experience

Ask what kind of support she
needs

Be a role model of body
appreciation

Advocate for patients with
lipoedema and body diversity

Conclusions for patients

ACT and Connect

Follow your dreams

Find your own voice

Find social support

Maintain healthy relationships

Take care of yourself

Take one step at a time

Dream big!

Change the world one person at a time

Lymf

Kalmar Län

Lymf- och lipödemförening

Thank you!

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