

# Psychological perspective on the quality of life of women with lipoedema

**Joanna Dudek, Ph.D.**

SWPS University of Social Sciences and  
Humanities, Warsaw, Poland



**Lymf**  
**Kalmar Län**  
Lymf- och lipödemförening

# Acknowledgments



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<http://tillysmidt.nl/>



Paweł Ostaszewski Ph.D.  
SWPS University of Social Sciences and  
Humanities, Warsaw, Poland



Wojciech Białaszek Ph.D.  
SWPS University of Social Sciences and  
Humanities, Warsaw, Poland



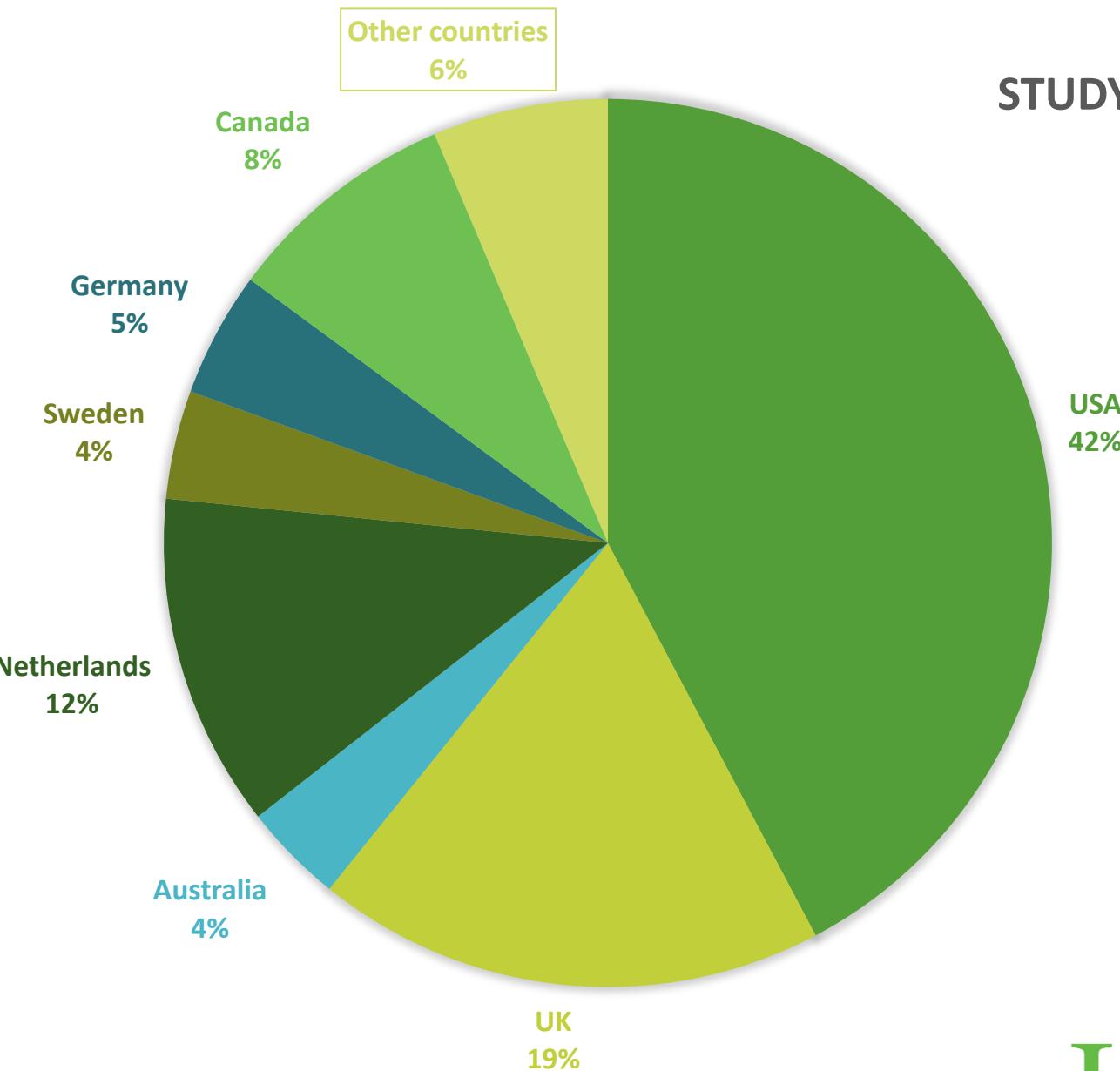
Jonathan Kanter Ph.D.,  
Center for the Science of Social Connection,  
University of Washington, Seattle

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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?

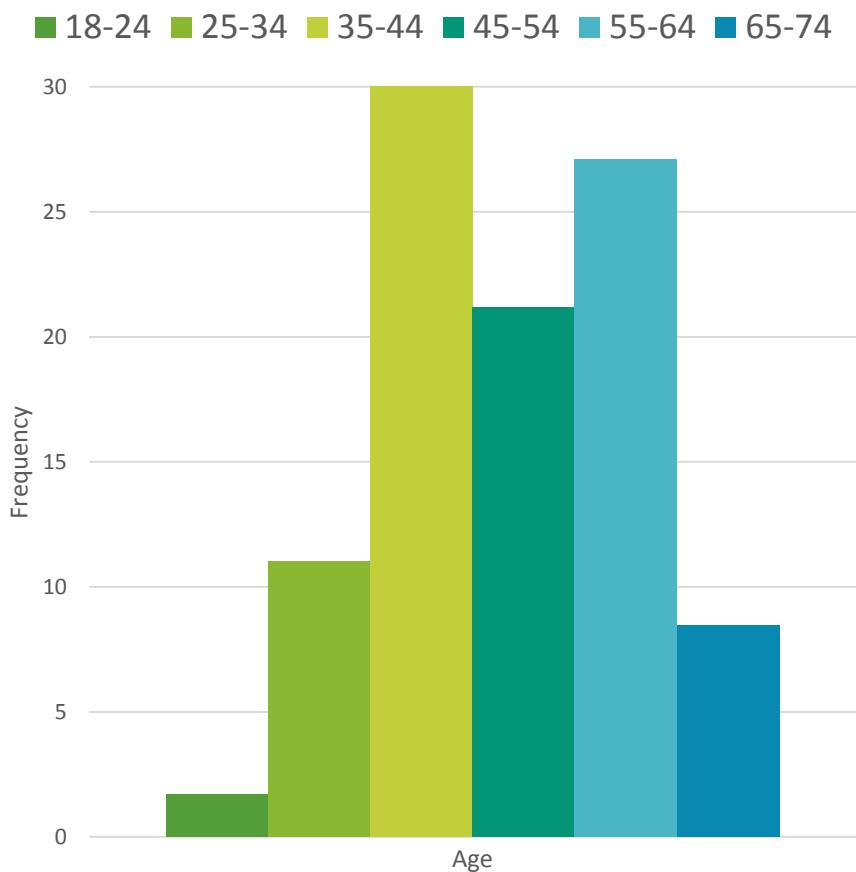
## STUDY 2



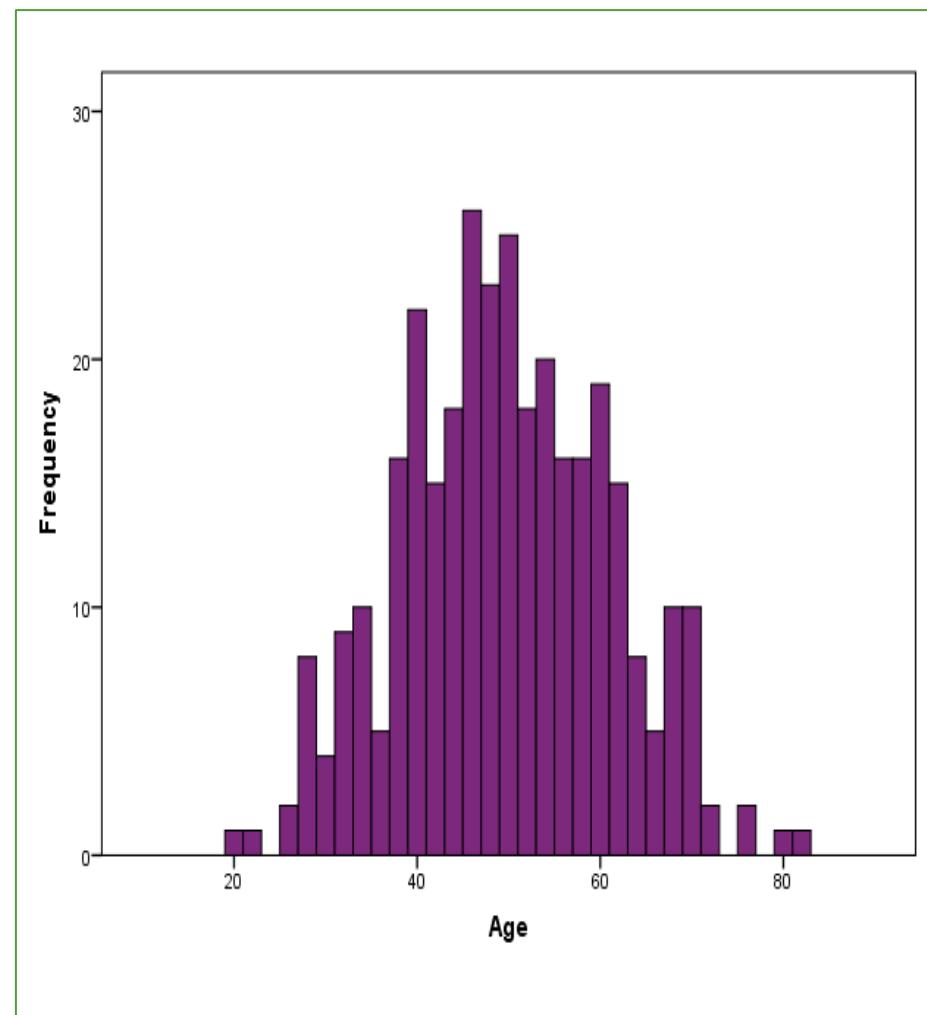
Dudek, J. E., Białaszek, W., Ostaszewski, P., & Smidt, T. (2018). Depression and appearance-related distress in functioning with lipedema. *Psychology, health & medicine*, 1-8.

# Participants' Age

**Study 1 N=118**



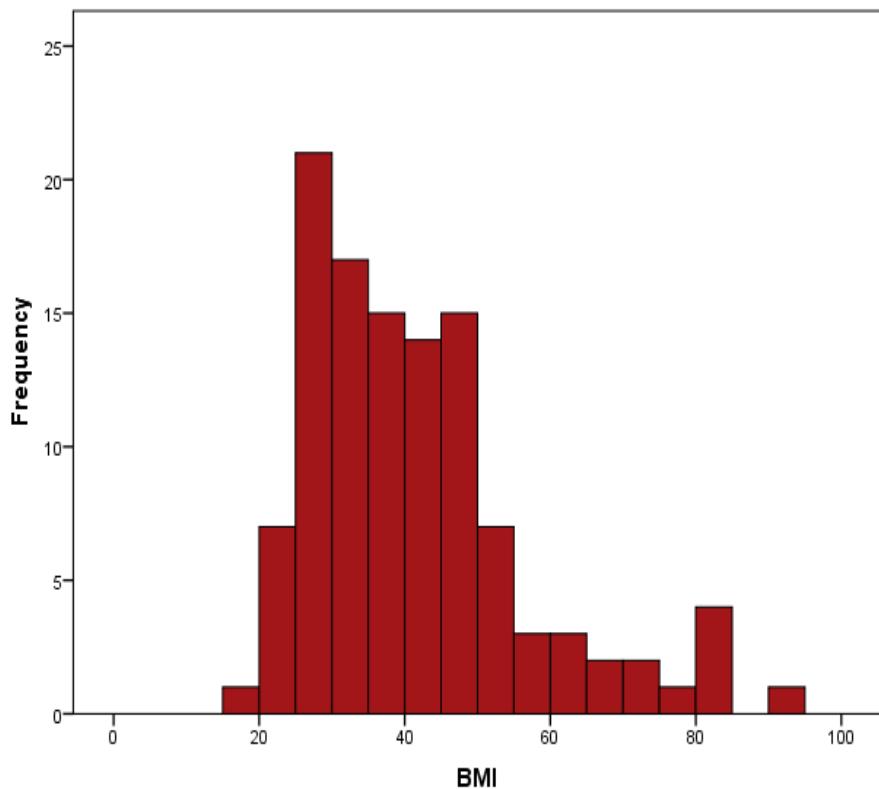
**Study 2 N=328 M=49.18; SD=11.24**



# BMI (Body Mass Index)

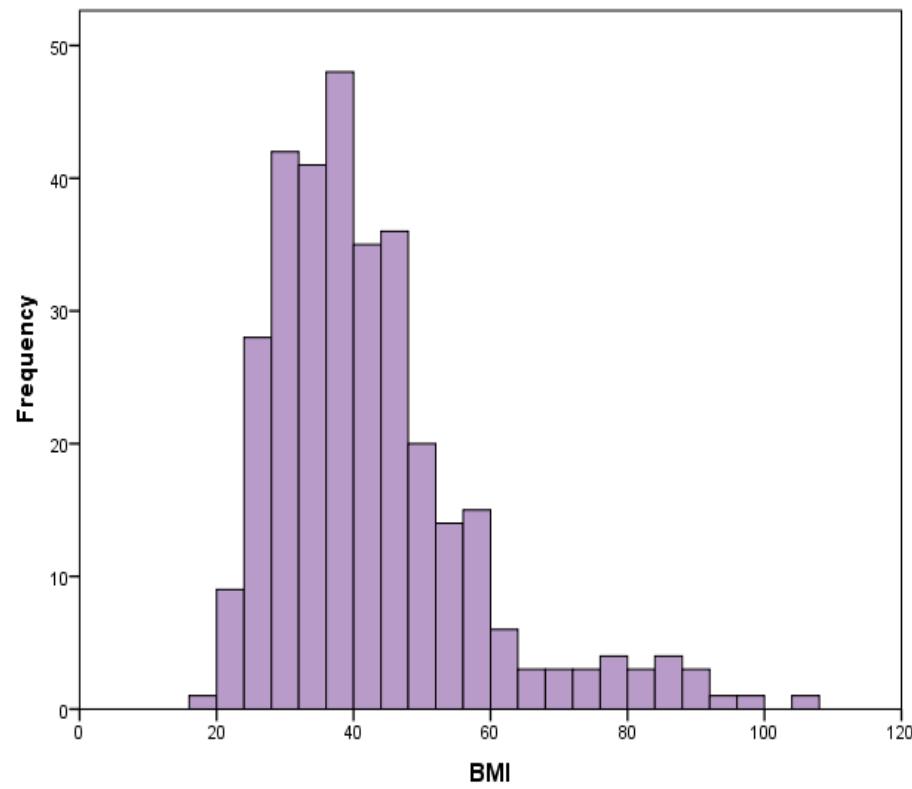
**Study 1**

**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

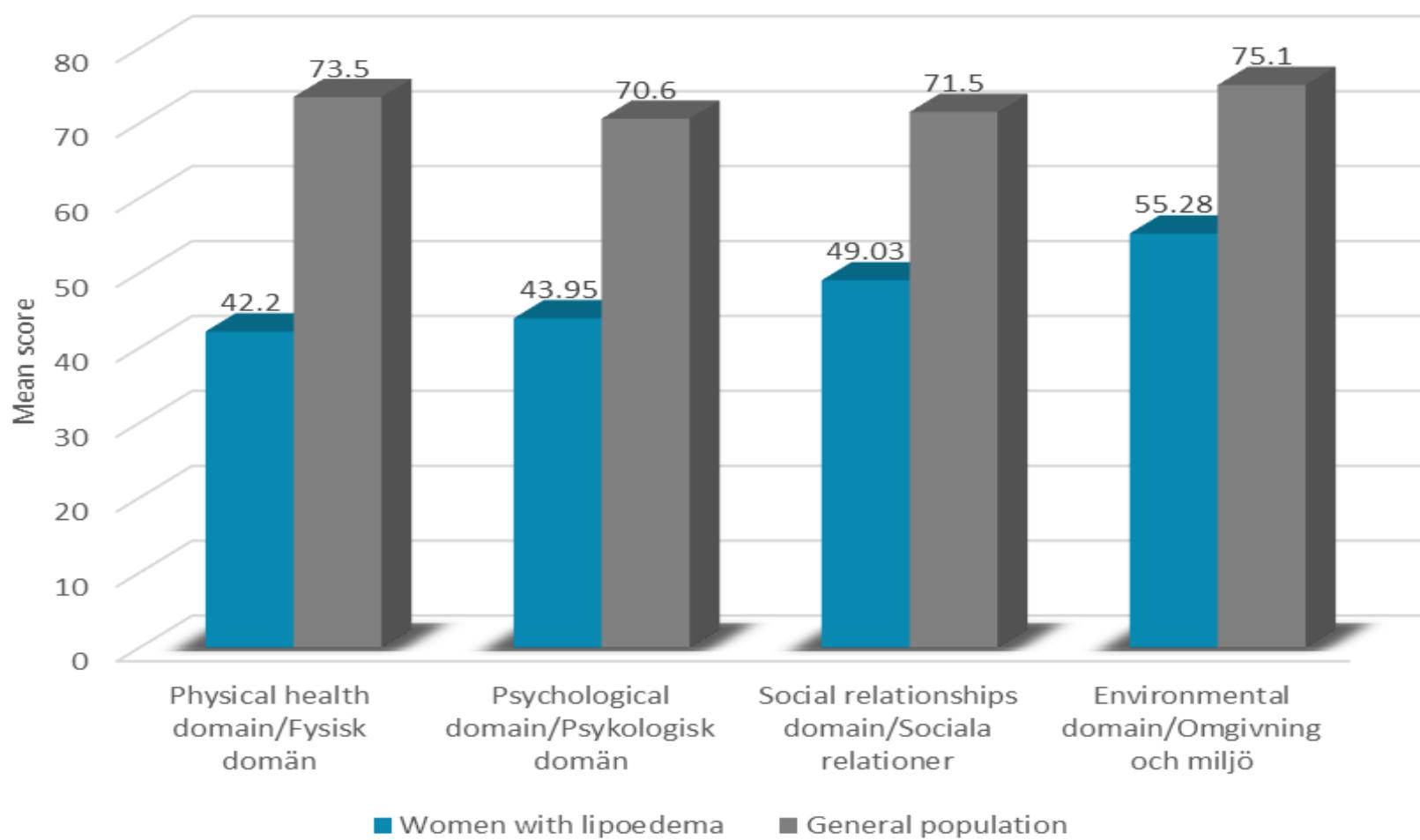
Psychological

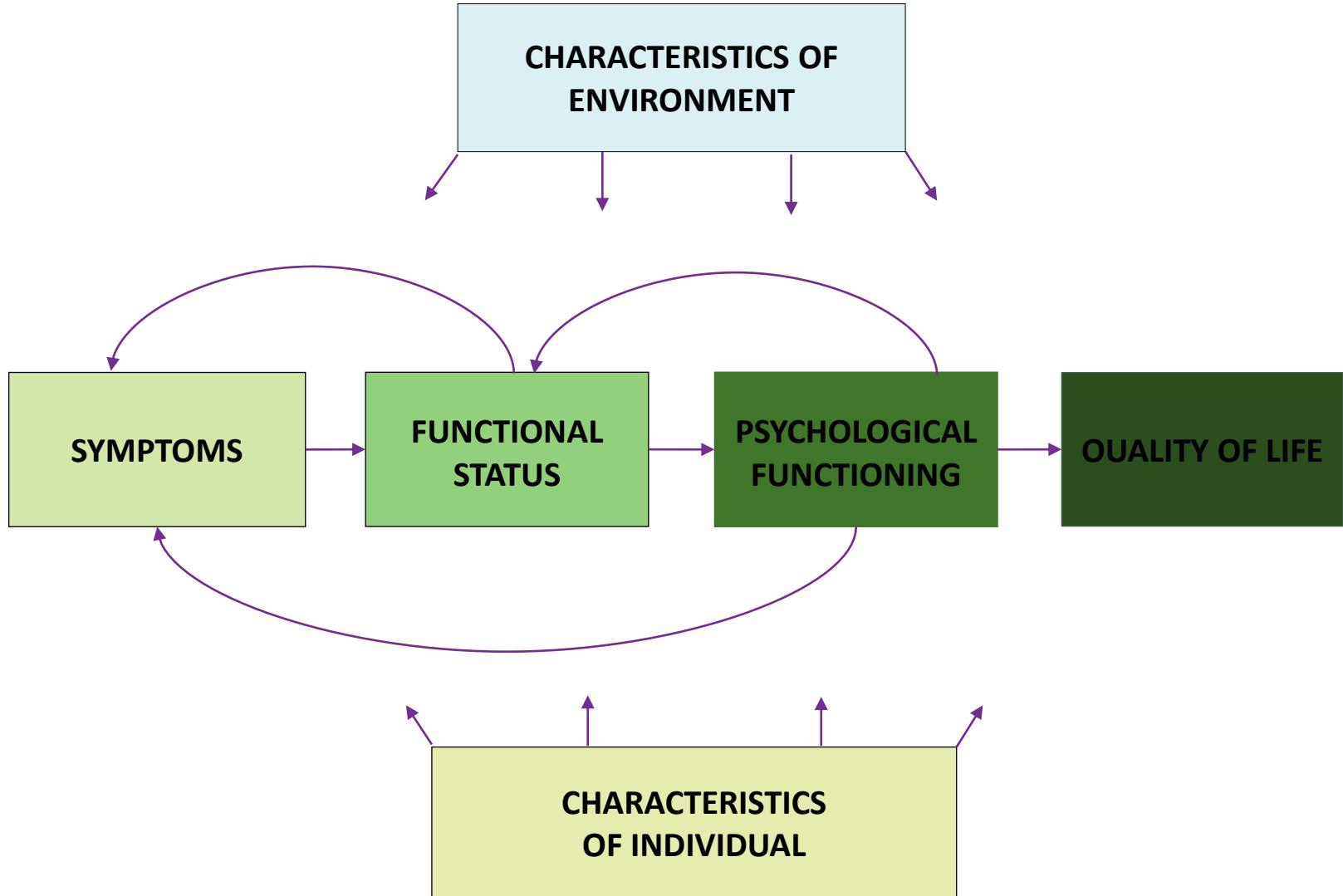
Social

Environmental

**Quality of life in women with lipoedema and in general population  
(WHOQOL-BREF, Transformed scores)**

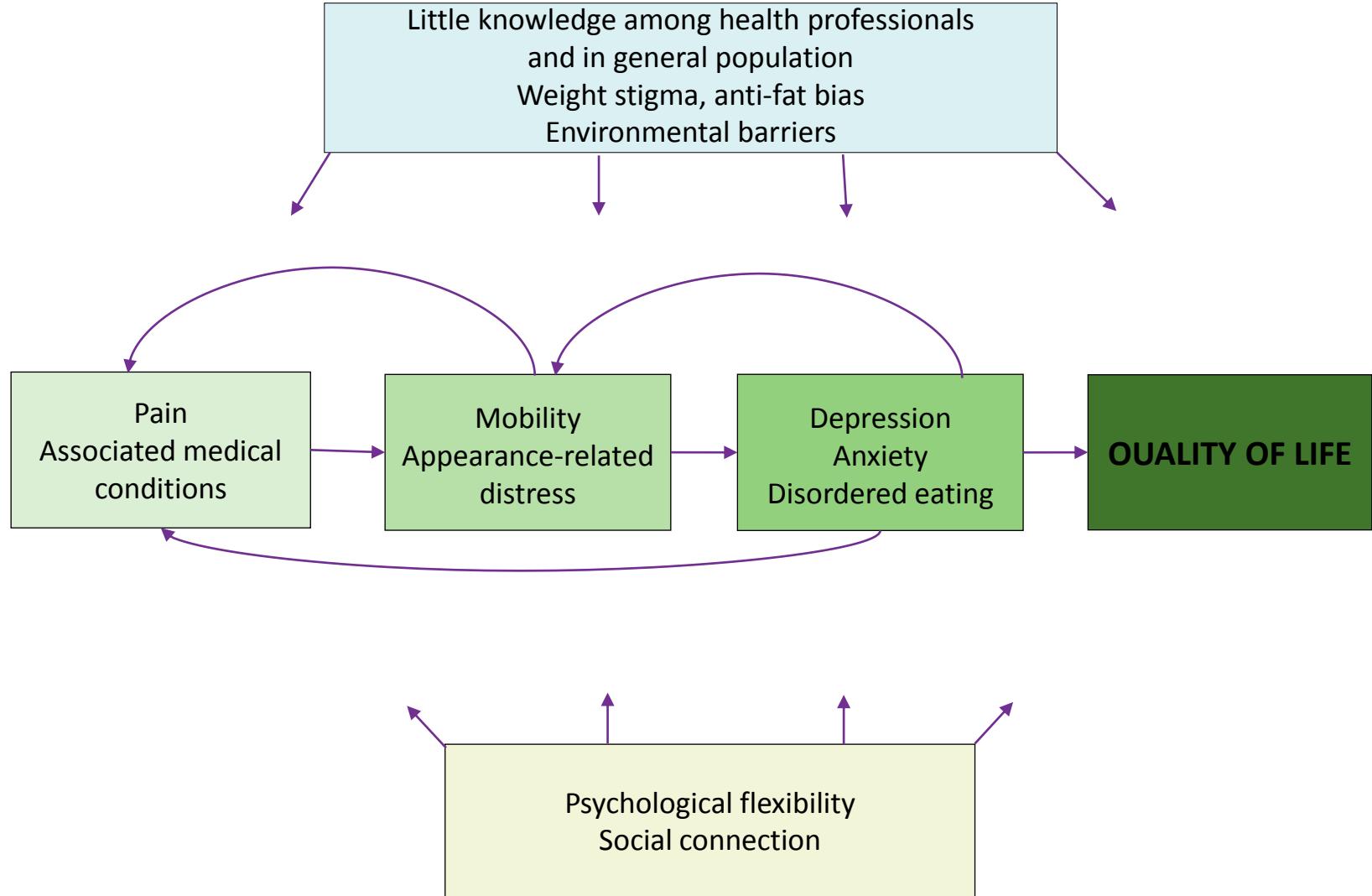
**Livskvalitet hos kvinnor med lipödem och befolkningen i  
allmänhet**





**Lymf**  
Kalmar Län  
Lymf- och lipödemförening

Based on: Wilson, I. B., & Cleary, P. D. (1995). Linking clinical variables with health-related quality of life: a conceptual model of patient outcomes. *Jama*, 273(1), 59-65.



# 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](#)

## Lipedema: A Relatively Common Disease with Extremely Common Misconceptions

[Donald W. Buck, II, MD](#)<sup>✉\*</sup> and [Karen L. Herbst, MD, PhD](#)<sup>†</sup>

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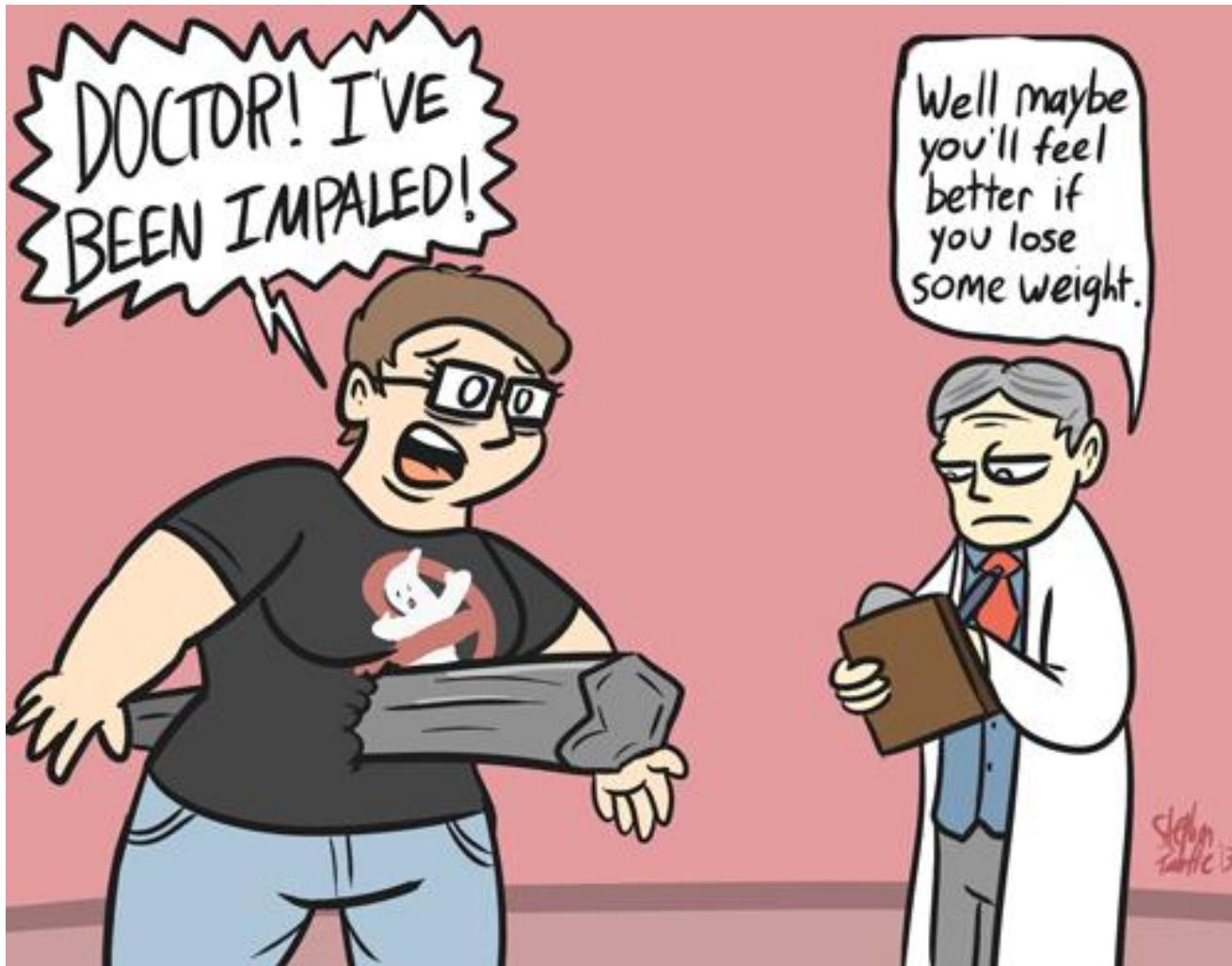
This article has been [cited by](#) other articles in PMC.

### Abstract

Go to:

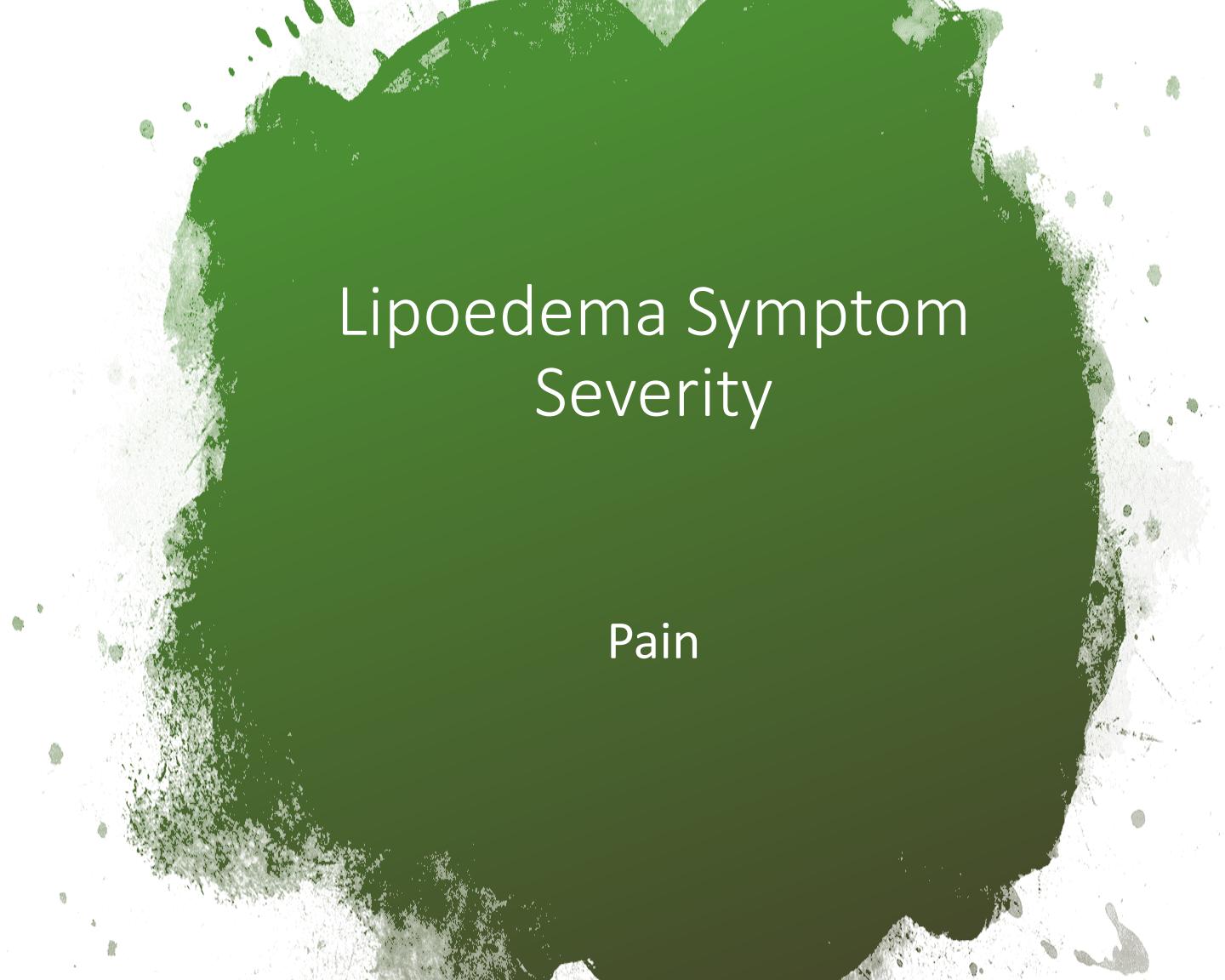
Lipedema, or adiposis dolorosa, is a common adipose tissue disorder that is believed to affect nearly 11% of adult women worldwide. It is characterized most commonly by disproportionate adipocyte hypertrophy of the lower extremities, significant tenderness to palpation, and a failure to respond to extreme 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

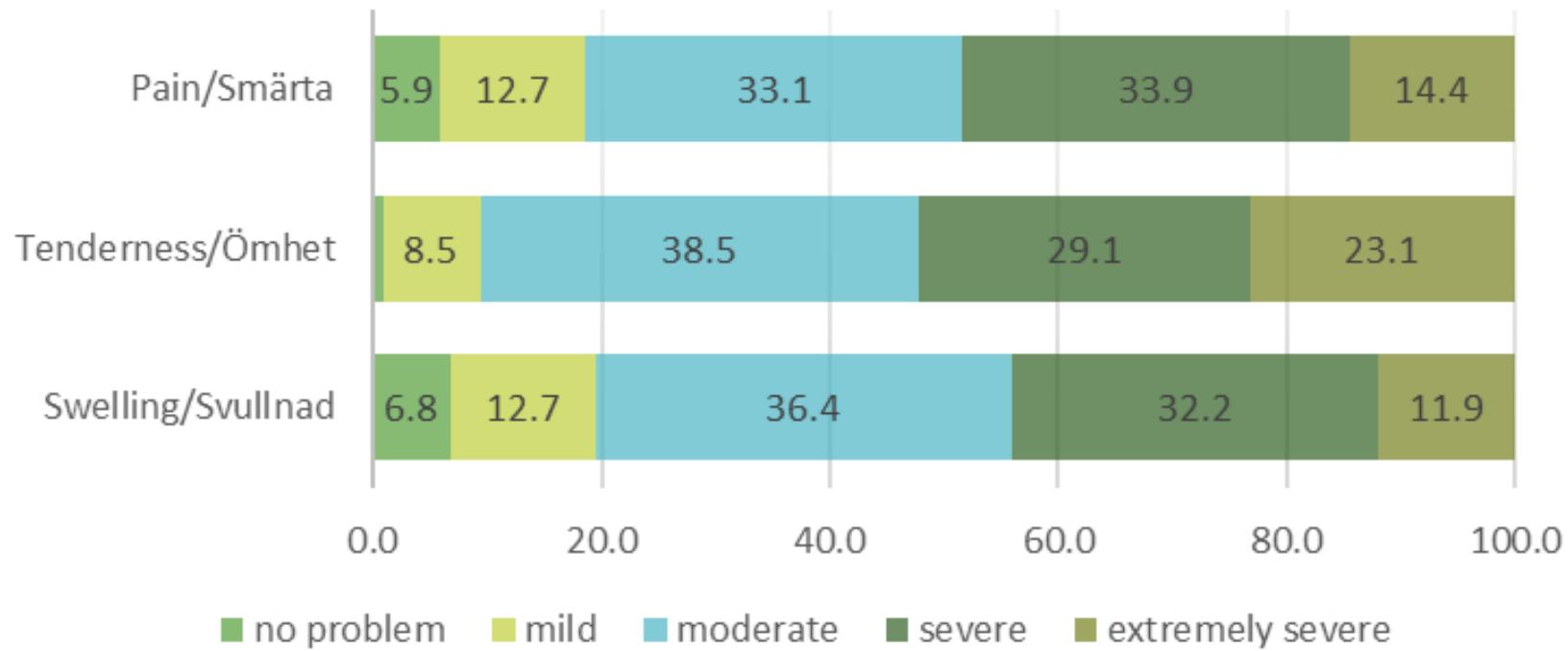




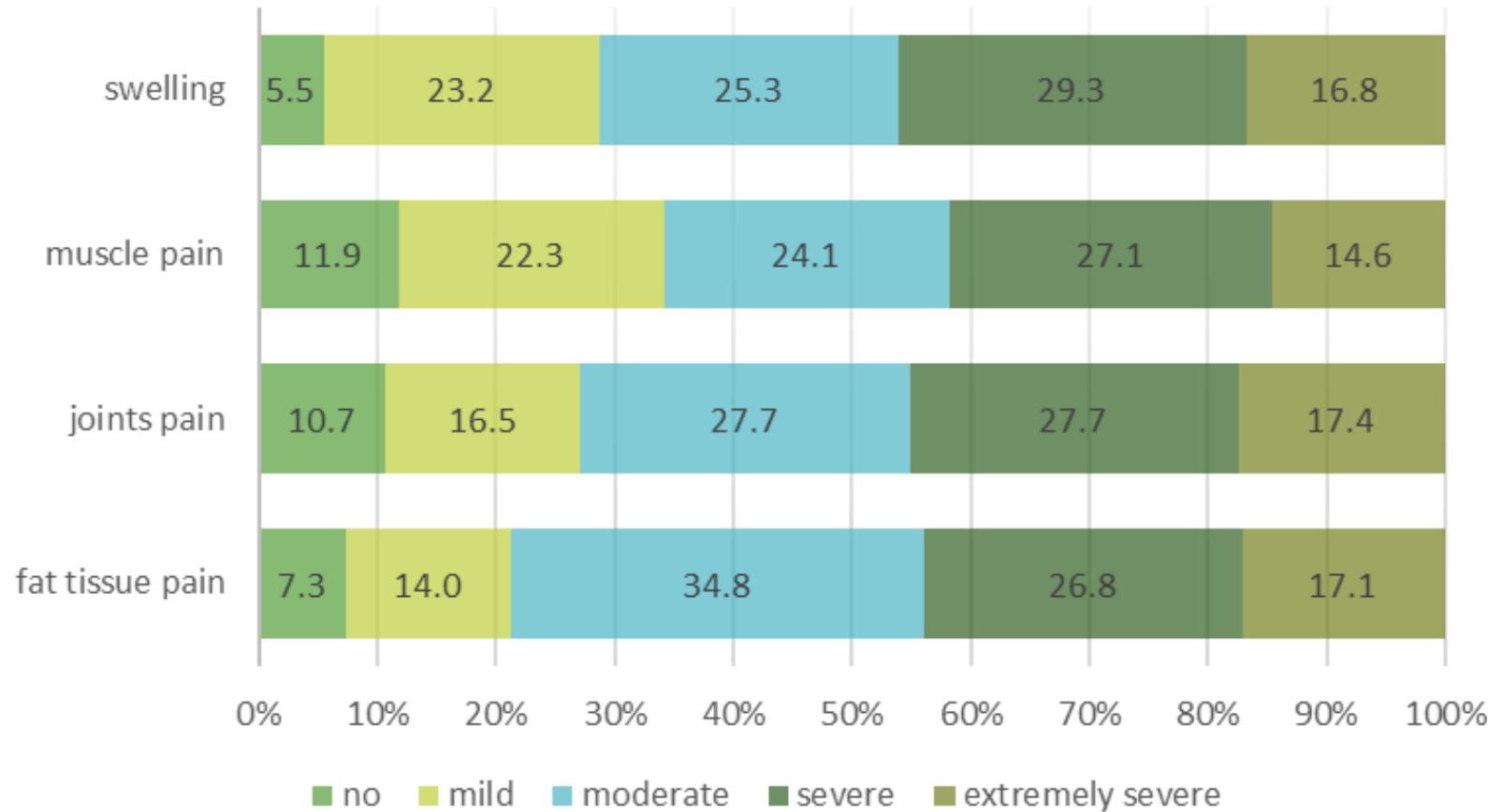
# Lipoedema Symptom Severity

Pain

# SYMPTOM SEVERITY/SYMPOTM SVÄRIGHETSGRAD (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

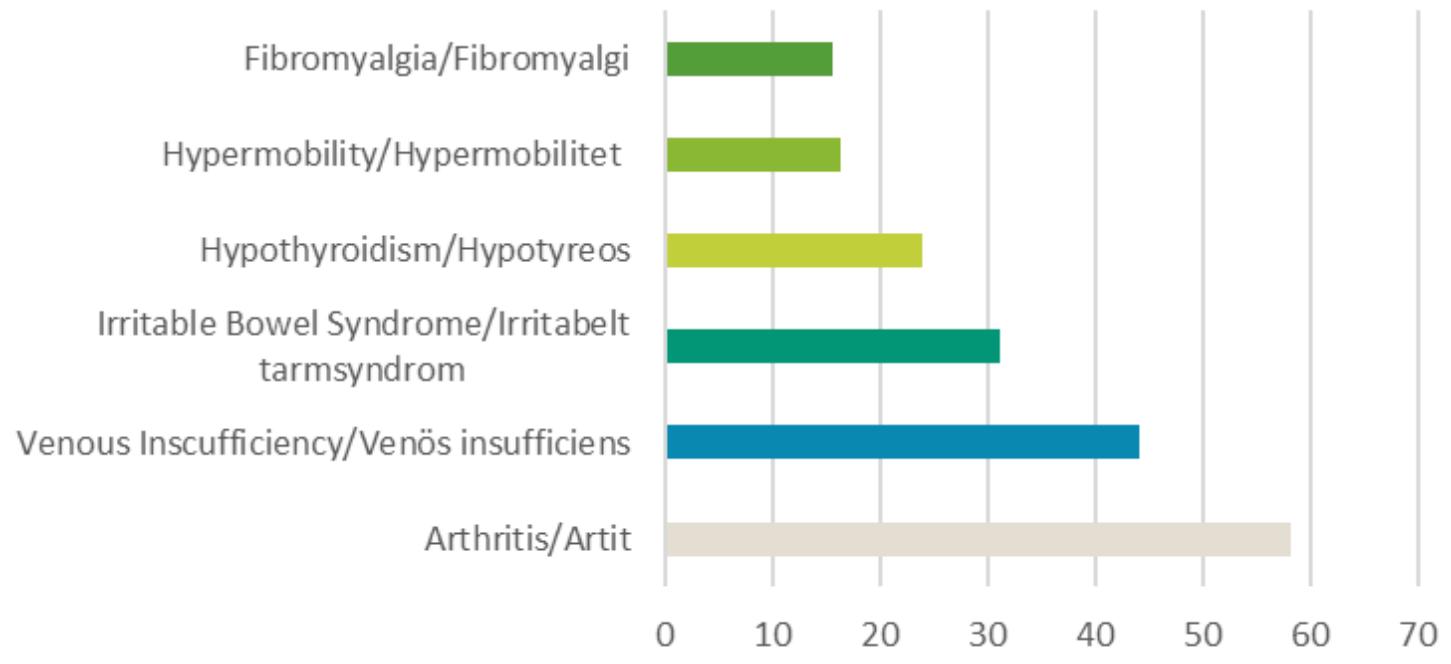
## Lower pain perception

- 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(%)



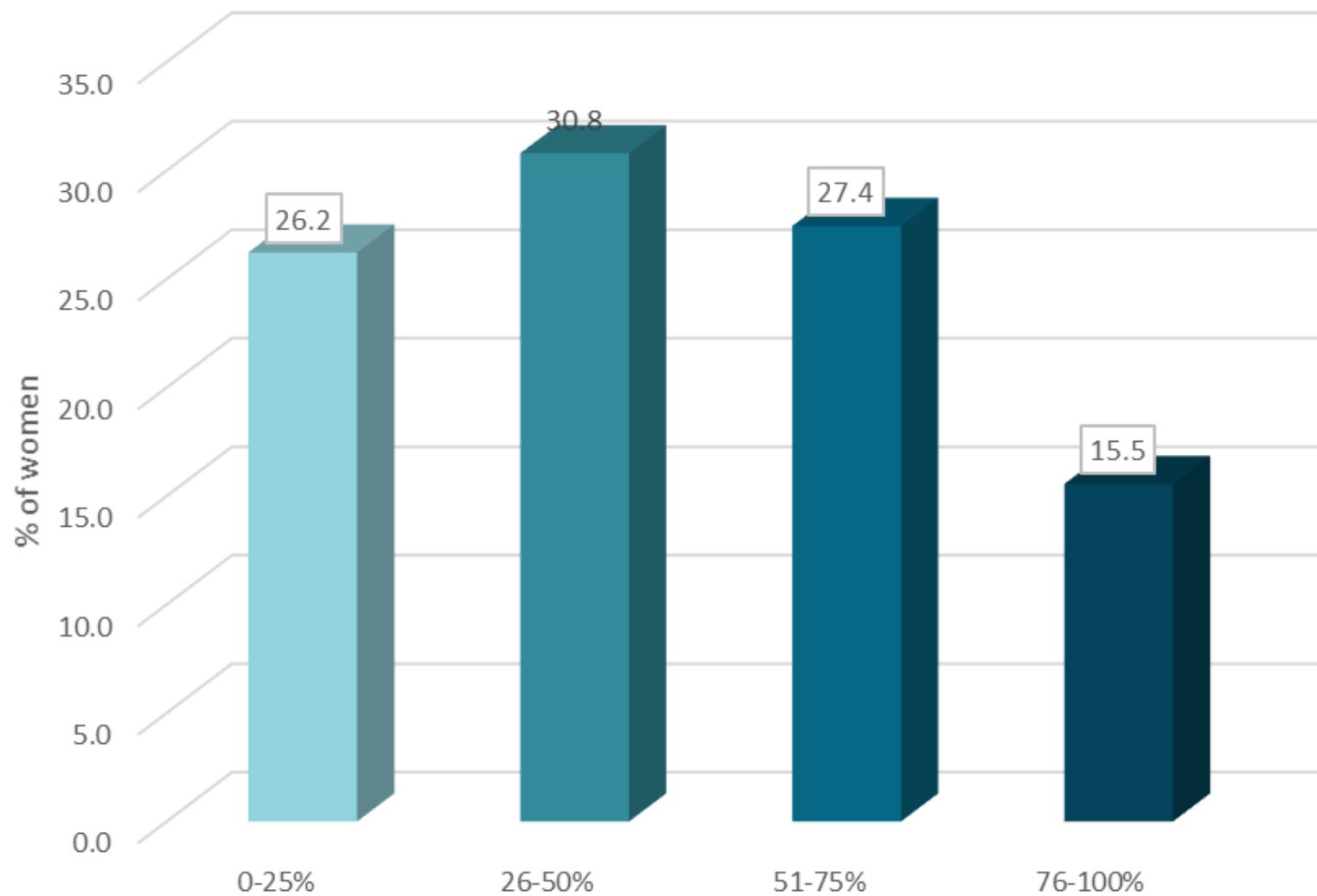
Associated medical conditions need further and more detailed investigation. They all may contribute to lower quality of life. Treatment needs to be individualized.



# 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

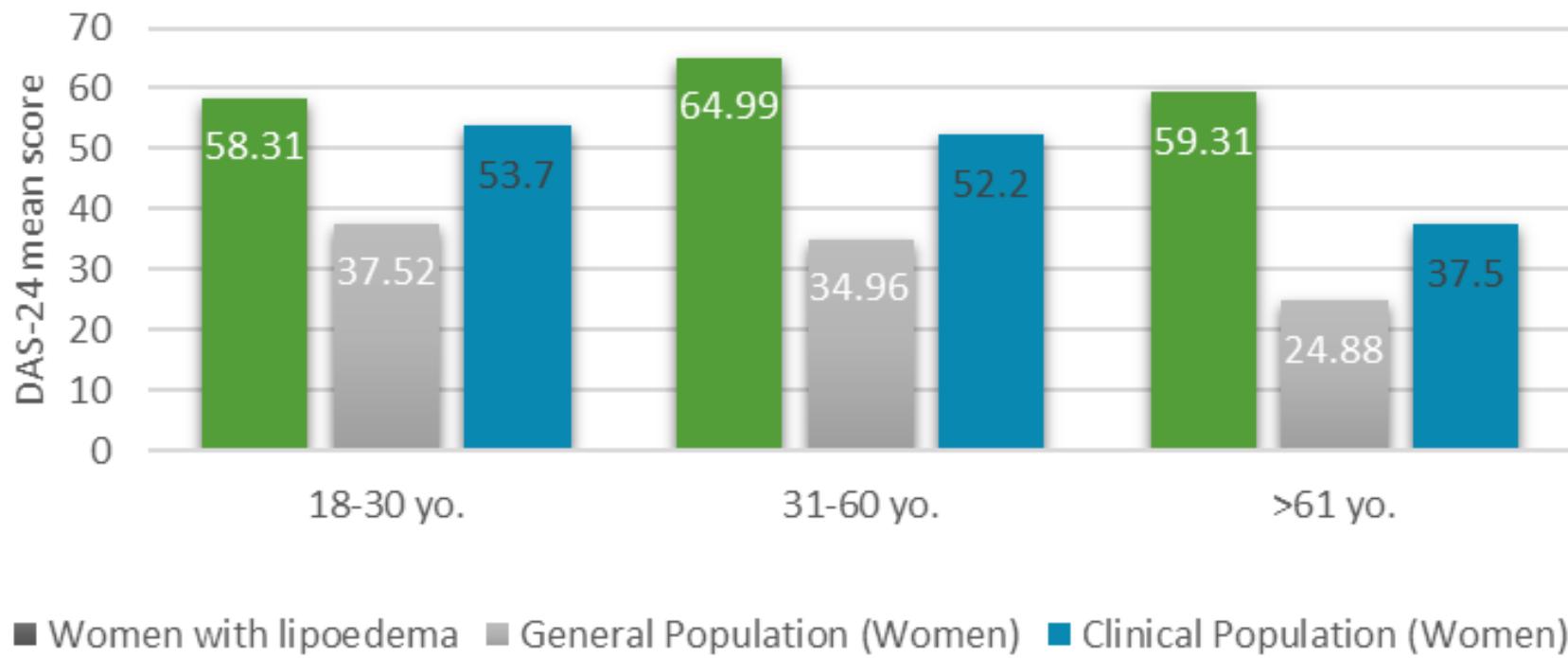
# Mobility from psychological perspective

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

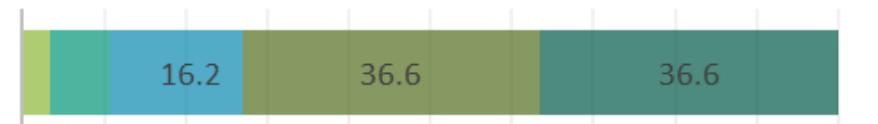
## Appearance related distress Utseende relaterad stress (DAS-24) (Study 2)



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>

# EXAMPLE QUESTIONS EXEMPEL FRÅGOR DAS-24

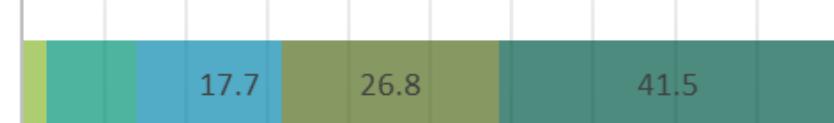
How distressed do you get when going to social events?



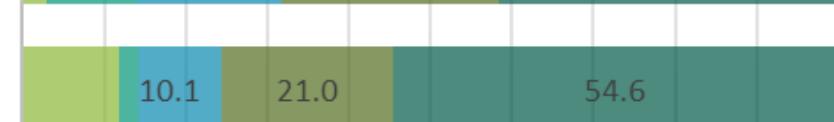
How distressed are you by being unable to wear your favorite clothes?



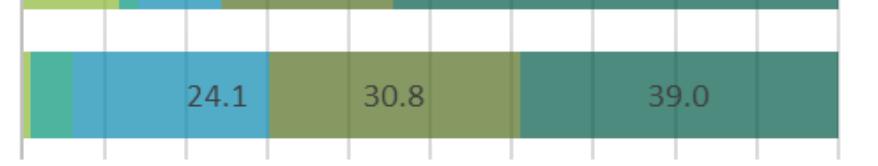
How distressed do you get by shopping in department stores/supermarkets?



How distressed do you get when you go to the beach?

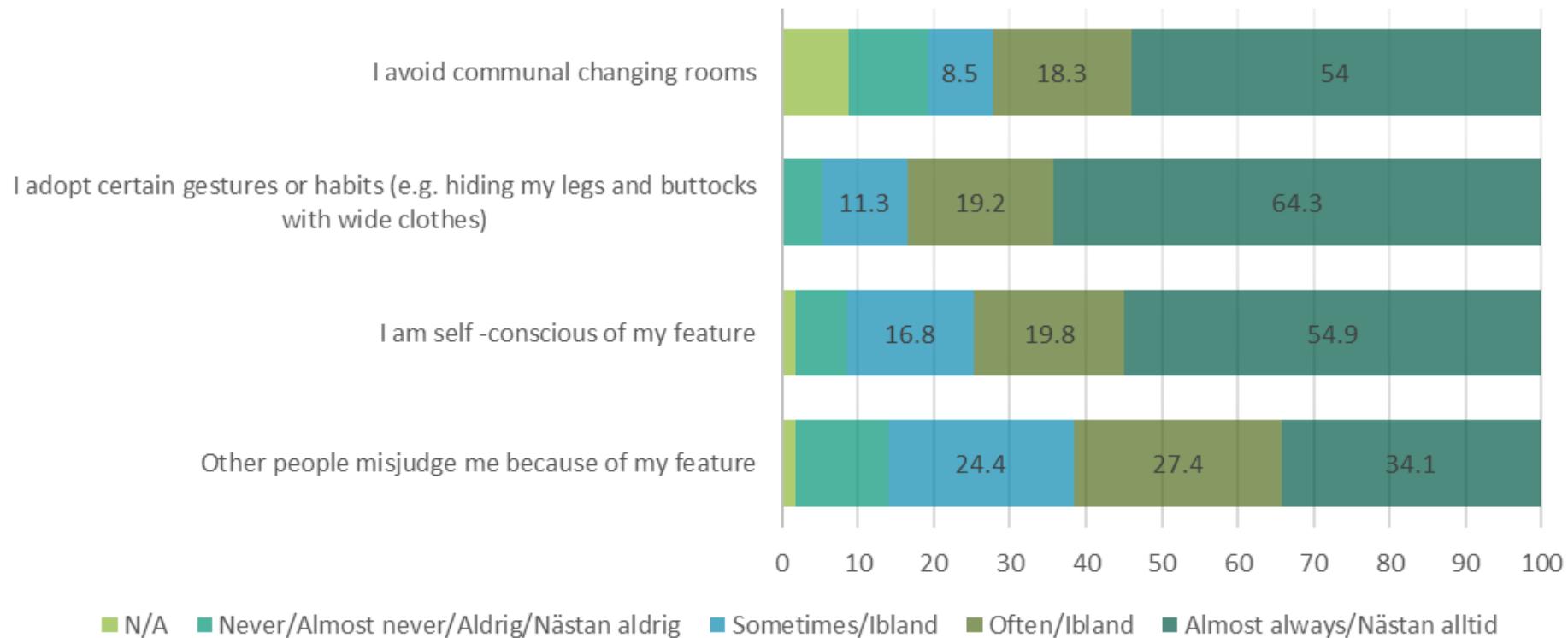


How distressed do you get when you see yourself in the mirror/window?



■ N/A ■ Not at all/Inte ■ Slightly/Lite ■ Moderately/Tämligen ■ Extremely/Ytterst

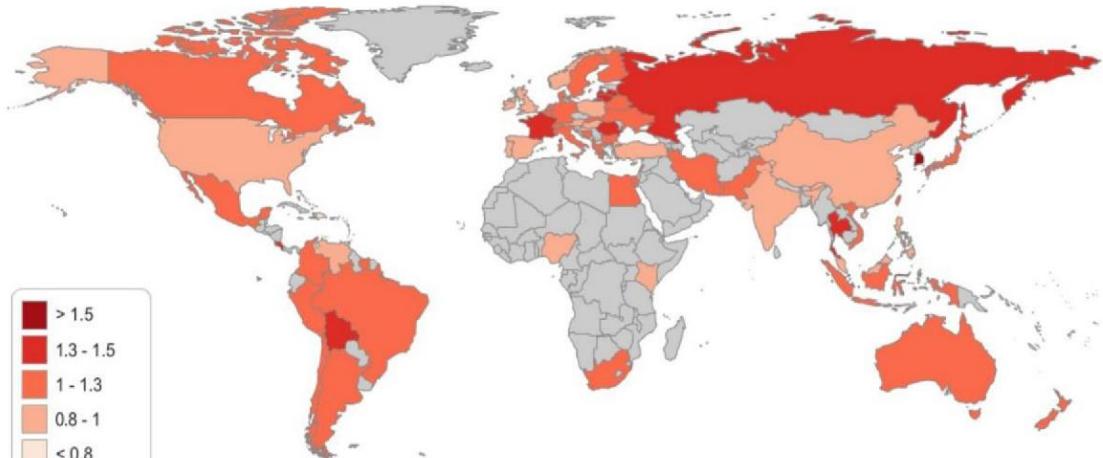
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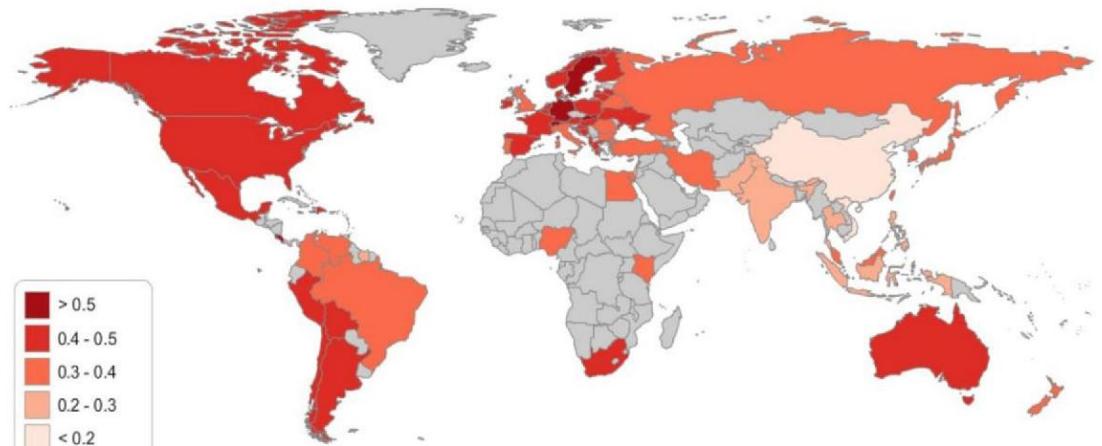
Carr, T., Moss, T., Harris, D. (2005). The DAS24: a short form of the Derriford Appearance Scale DAS59 to measure individual responses to living with problems of appearance. British Journal of Health Psychology, 10 (Pt 2), 285–298.  
<http://doi.org/10.1348/135910705X27613>

# Weight stigma is prevalent

Explicit weight stigma measures based on the Attitudes to Obese People (ATOP) scale



Implicit weight stigma measures based on Implicit Association Tests (IAT)



# Weight stigma affects health

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

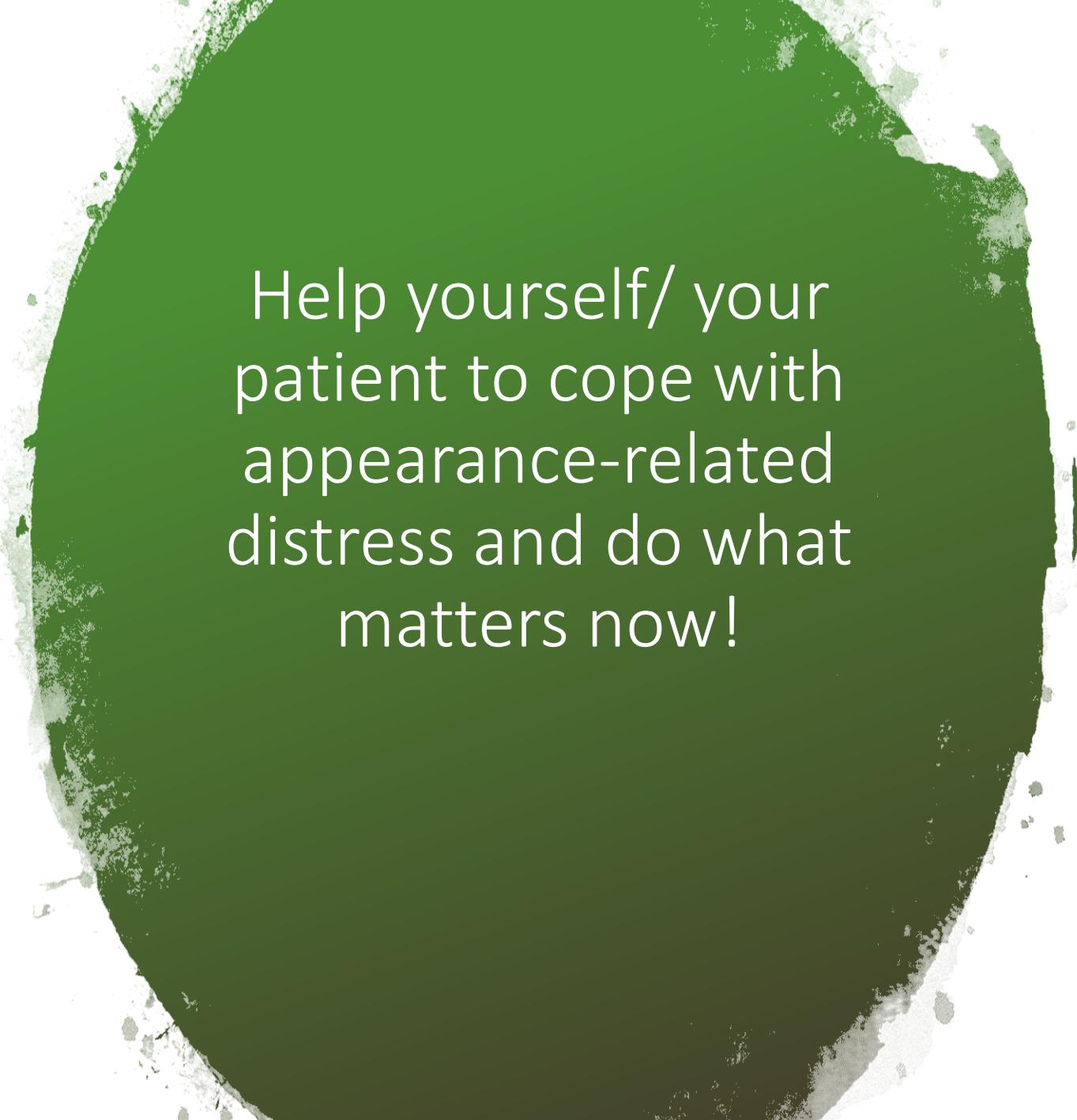
„Evidence collectively demonstrates negative implications of stigmatization for weight-related health correlates and behaviors ”

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

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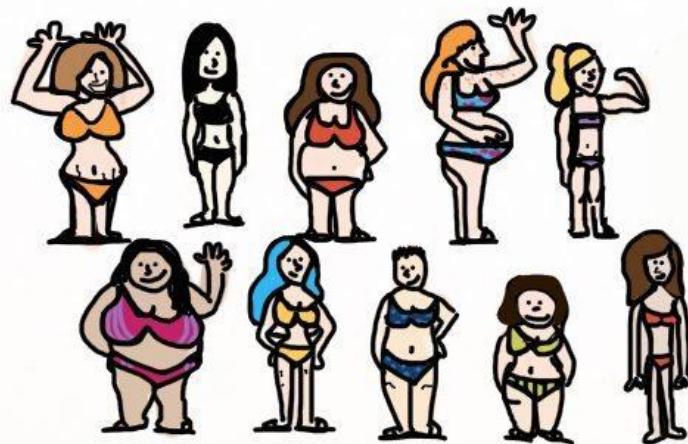
Sculpture „Paris Pekin“ by Marie  
Madeleine Gautier  
<http://www.mmgautier.fr>

# 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

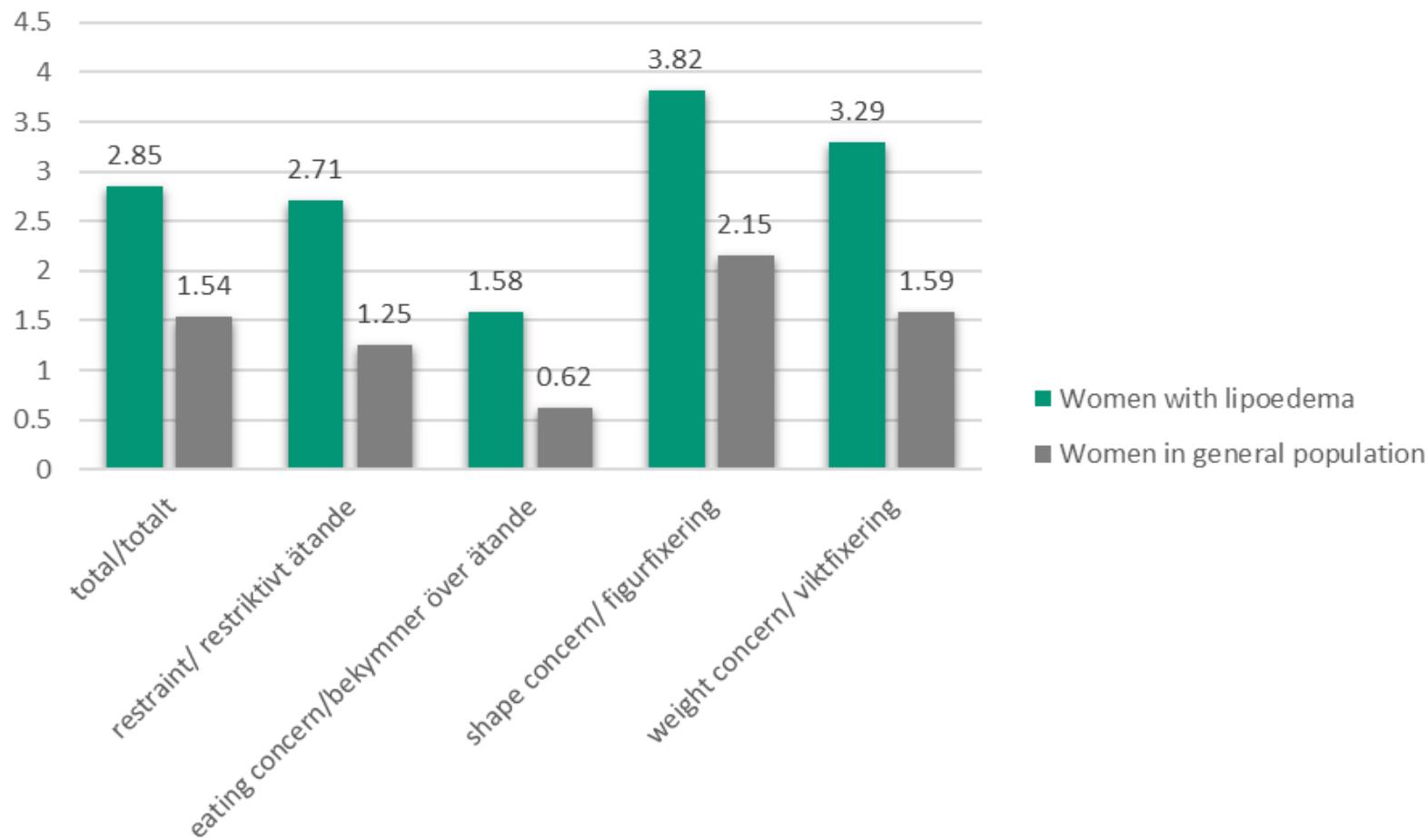
Binge-eating episodes

Purging after meals (compensatory  
behaviors)

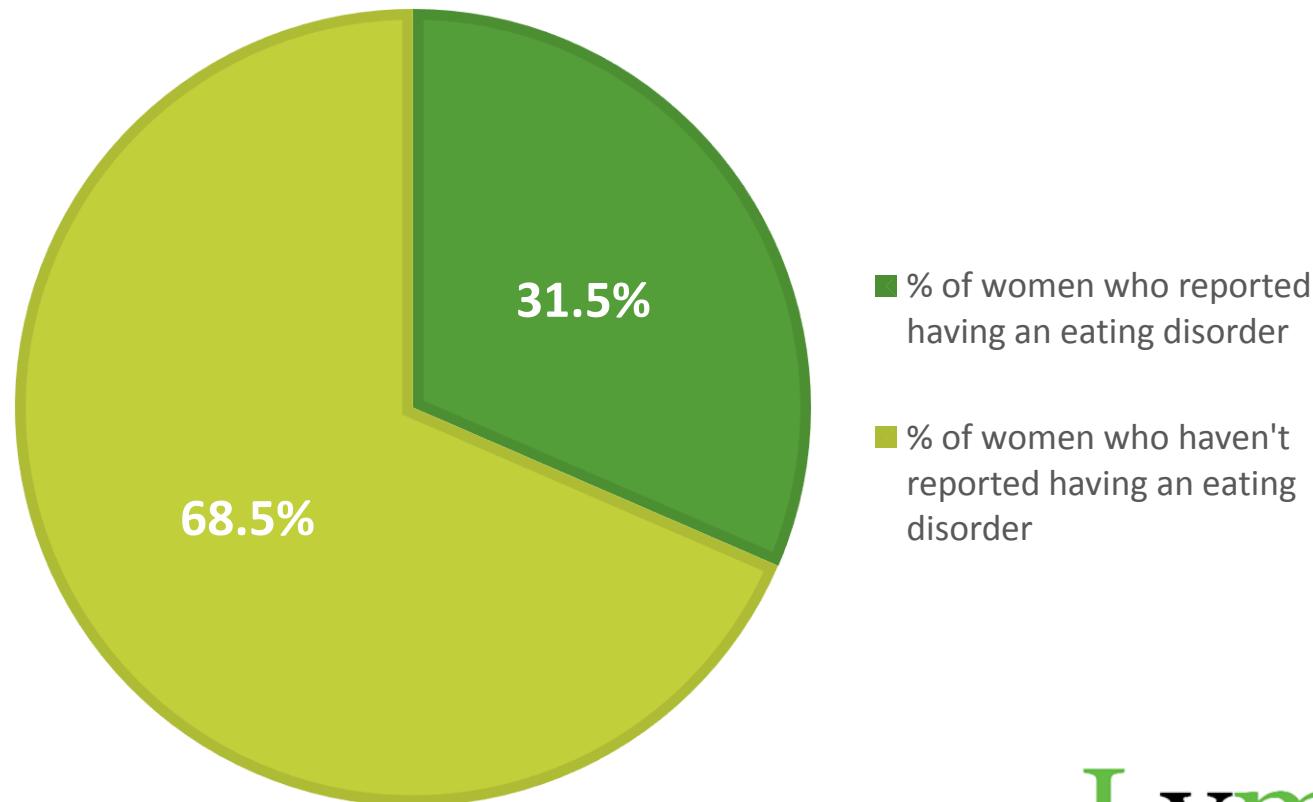
Shame related with eating

Self-evaluation based on shape/weight

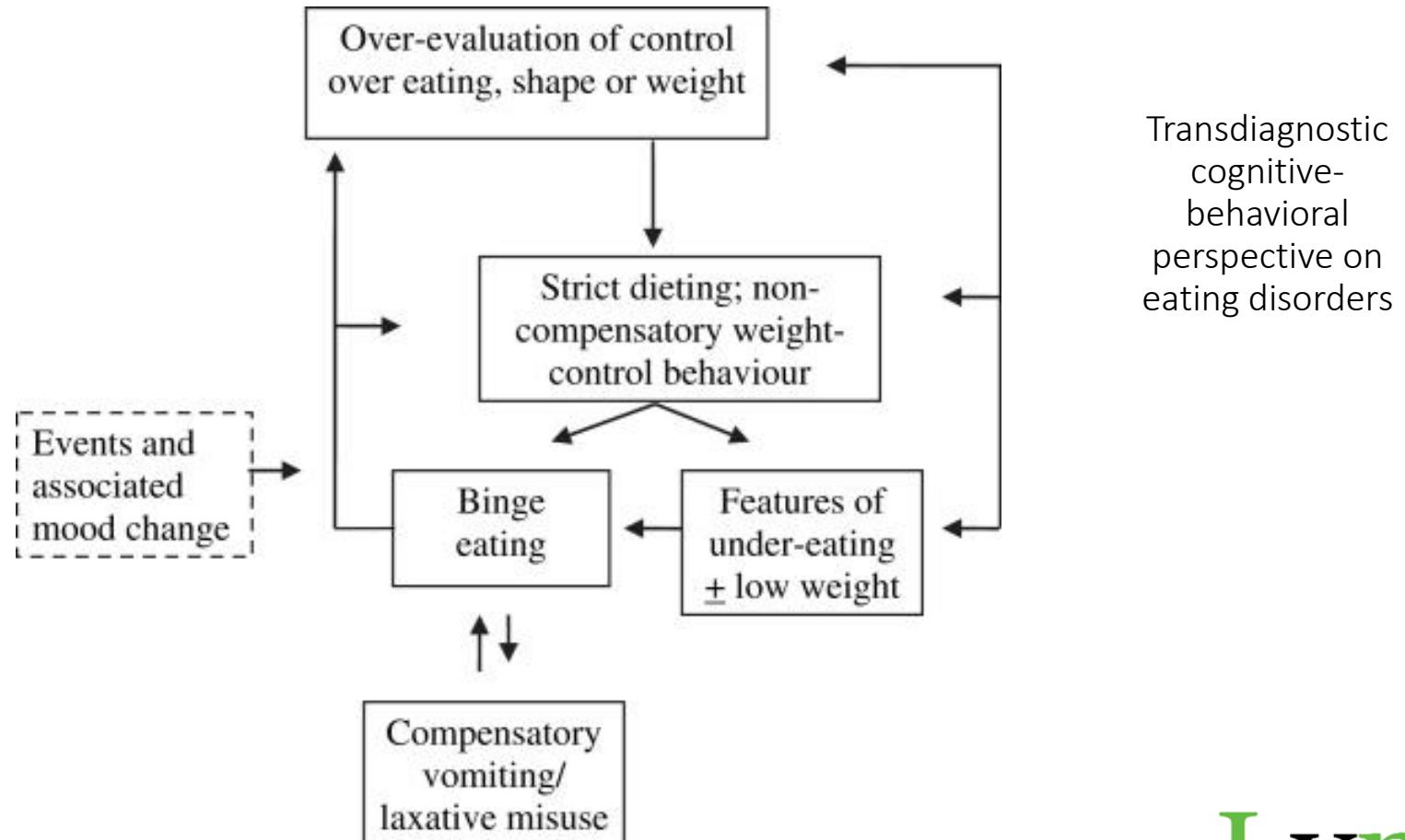
EDE-Q (mean score) in women with lipoedema and in women in general population  
EDE-Q (medelvärde) hos kvinnor med lipödem och hos kvinnor i allmän befolkning (Study 1)



# Self-reported eating disorders Självrapporterad ätstörningar (Study2)



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



# 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

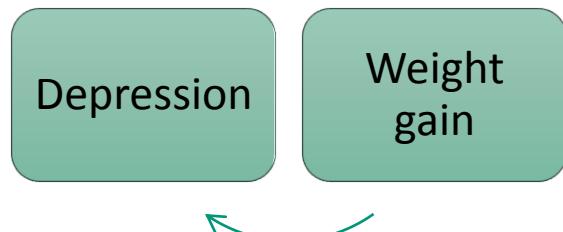
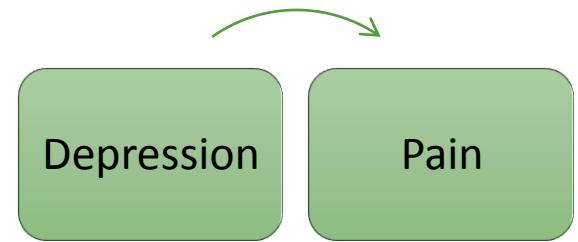
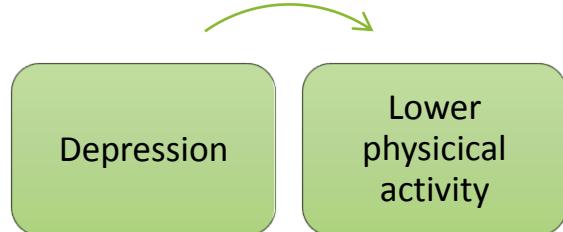


# Why women with lipoedema are at risk for depression?

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

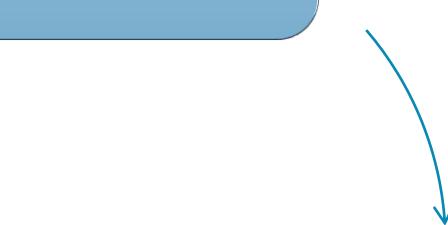
Walker, A. K., Kavelaars, A., Heijnen, C. J., & Dantzer, R. (2014). Neuroinflammation and comorbidity of pain and depression. *Pharmacological reviews*, 66(1), 80-101.

# Vicious circles of depression



Loss of positive reinforcement  
(e.g. social interactions,  
success etc.)

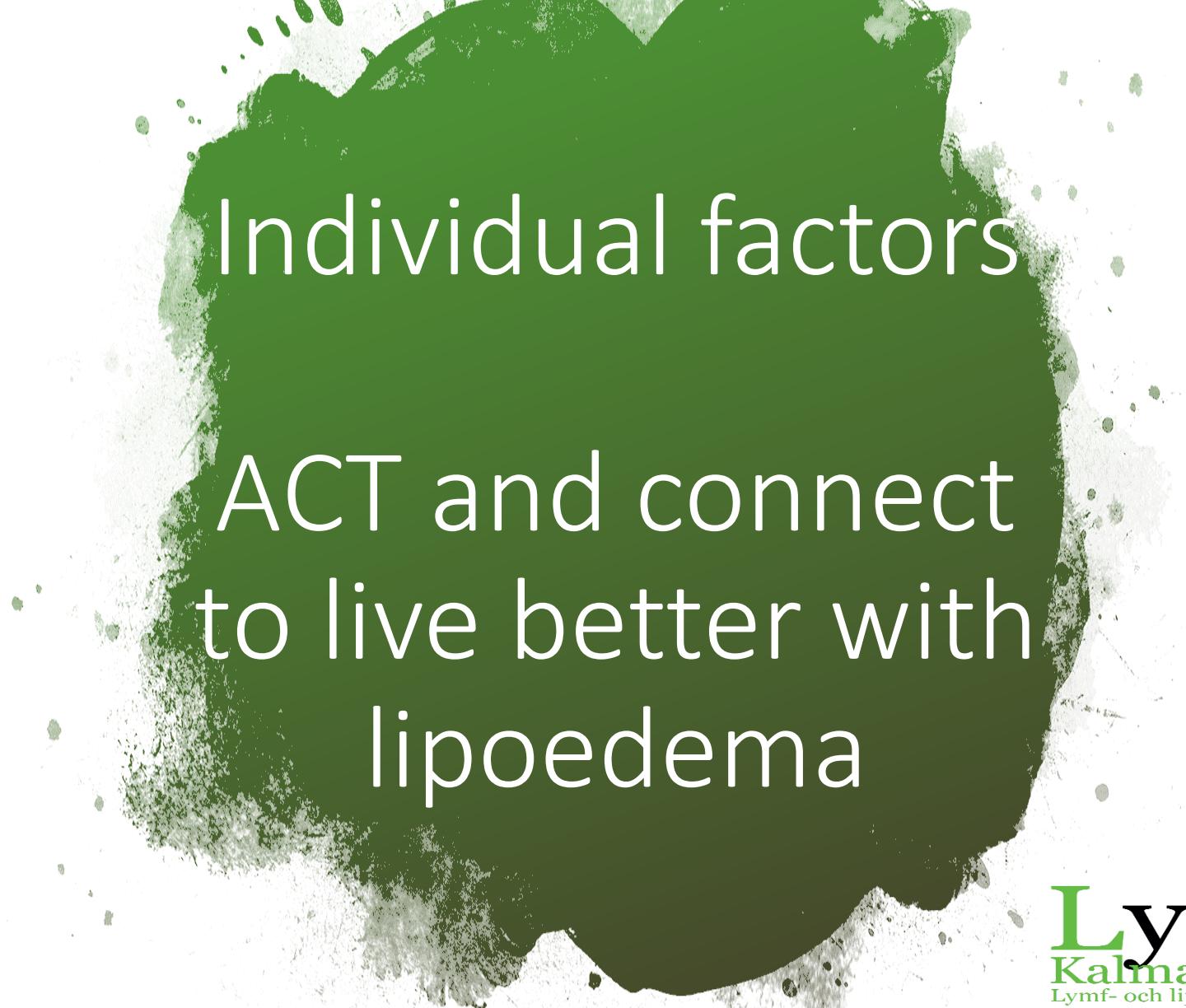
Staying indoors



Depression

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 flexibilitet)



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

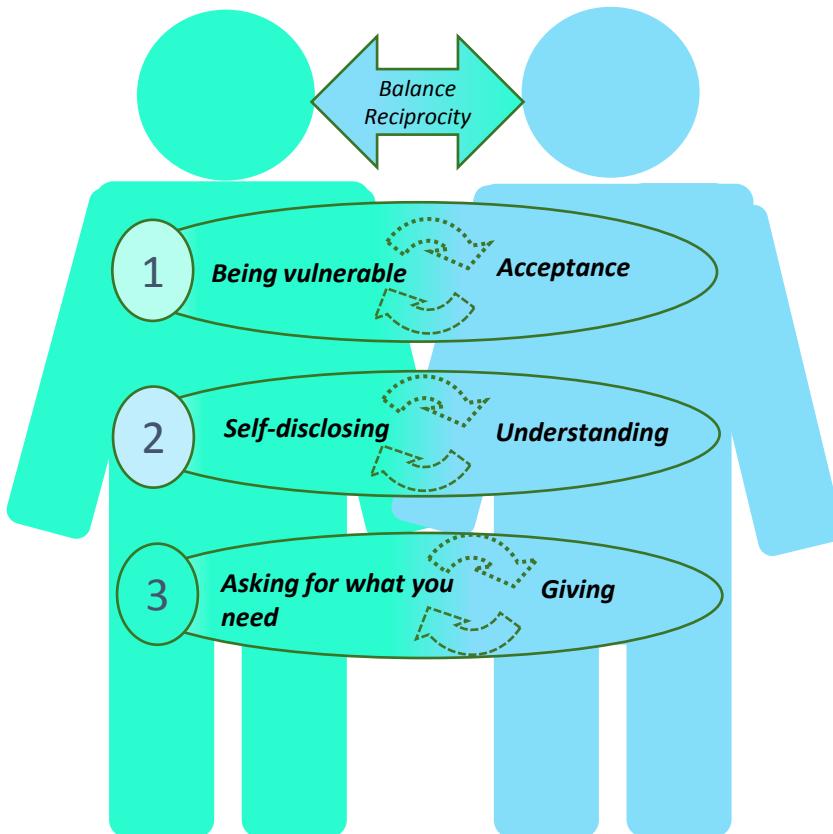
Engage in important activities even in the presence of pain or discomfort

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)

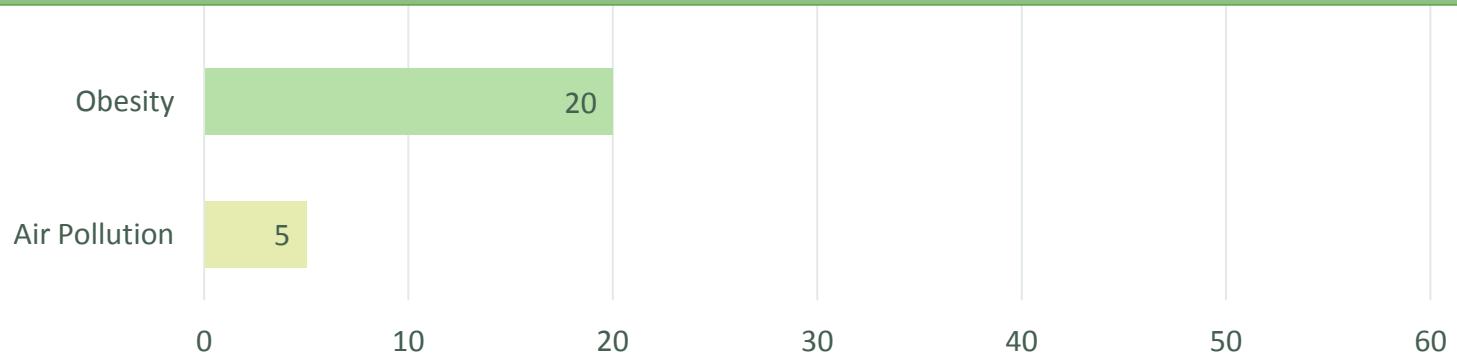
# CONNECT (Social Connection)



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



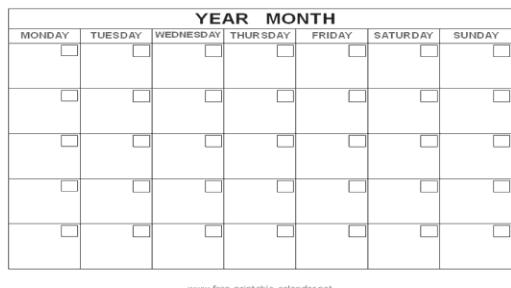
- Lab “conflict interaction”
- Classified as “high conflict” or “low conflict”

Step 2



- Each participant given “suction blister” wound

Step 3



- Measure number of days for full healing of wounds

Kiecolt-Glaser; Loving; Stowell; Malarkey; Lemeshow; Dickinson; Glaser  
*Arch Gen Psychiatry*. (2005) Hostile Marital Interactions, Proinflammatory Cytokine Production, and Wound Healing ;62(12):1377-1384.

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!

[jdudek@swps.edu.pl](mailto:jdudek@swps.edu.pl)

[joannaedudek@gmail.com](mailto:joannaedudek@gmail.com)