Self management & compression

ICC Maastricht 2014
13th May 2014

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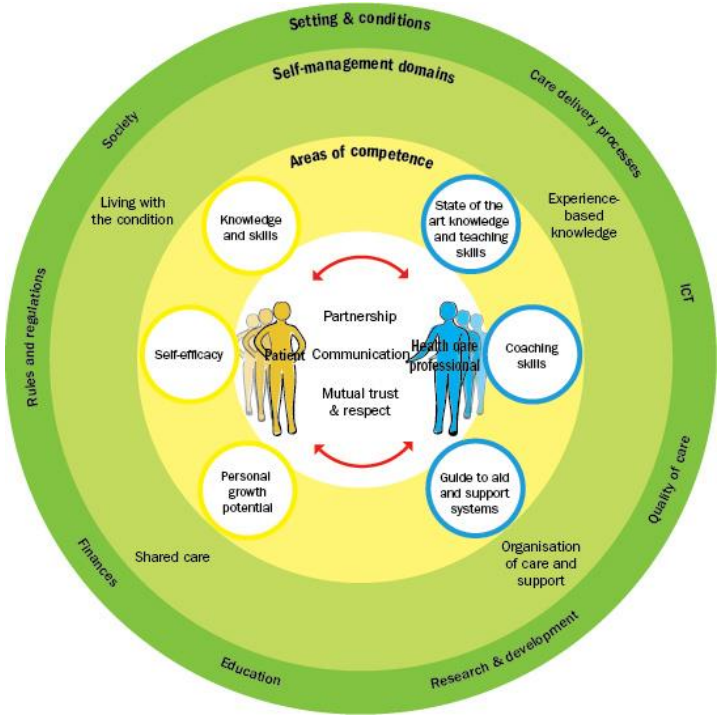
nij smellinghe
Expertisecentrum Lymfologie - Drachten

OEDEMA.BE

Definition

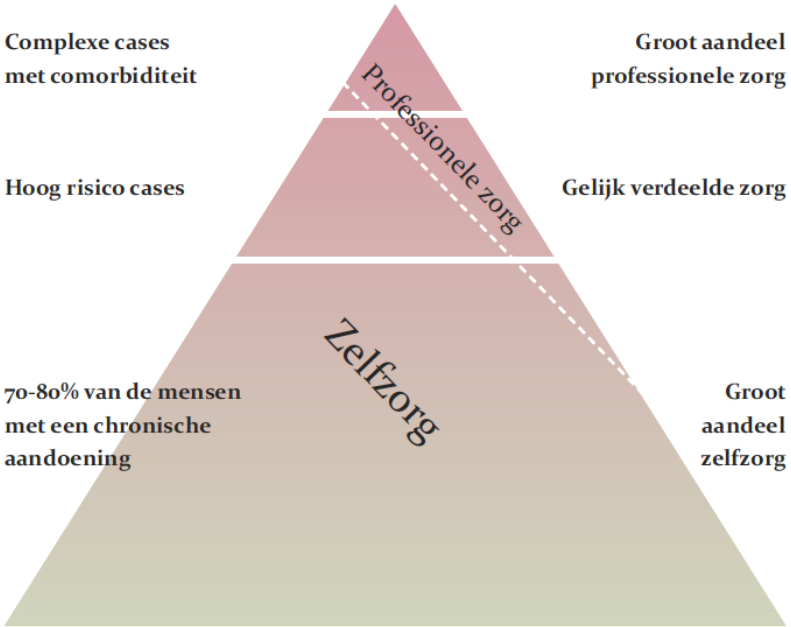
- Taking responsibility
- Participating
- Disease management
- Decision making
- With or without help

Patient/health professional joint venture



www.zelfamanagement.com

Which percentage?



Bron : NIVEL rapport 2011

Self management in percentages

pilot	steward(es)	passenger
20%	60%	20%

AWARENESS

Awareness askes for (emotional)intelligence

Expectations in chronic care

Why self management?

‘Political’ reasons:

- Increase chronic diseased patients
- Affordability of high quality care
- Responsibility patient

Other reasons:

- Connecting to modern view on care
- Increase self efficacy
- ICF

Self management & compression

Back ground and purpose

- No specific questionnaire available:
  - To assess effect of compression
    - In patients with arterial, venous disease and lymphoedema
    - On:
      - ICF
      - Patient satisfaction
      - Complications
      - Treatment compliance
- Prof. Partsch and prof. Mosti developed compression questionnaire: not tested on reliability and validity

- Purpose: to investigate, test-retest reliability and face validity of compression questionnaires

Methods

- Patients
  - 18 patients with lymphoedema wearing compression garments
  - Recruited:
    - Several practises (the Netherlands)
    - Leuven Lymphoedema Center (Belgium)

- Filled out
  - the compression questionnaire twice (N=15)
  - a questionnaire to assess face validity:
    - were questions understandable, was scoring system obvious, was questionnaire complete?

Methods

- Compression questionnaire
  - General information (filled out by practitioner)
  - Information about compression device (filled out by patient)
    - Wearing information
    - Easiness of handling
    - Comfort of compression device
    - Symptoms (without compression device)
    - Side effects of compression
    - Mental effect
    - General assessment

Results – patients

- 18 patients with lymphoedema
  - 15 patients filled out compression questionnaire twice
  - Avarage age: 56 years
  - BMI: 26,6
  - Side with compression: 6 bilateral, 8 left side, 4 right side
  - Region with compression
    - 9 arm lymphoedema: 3 arm, 5 arm and hand, 1 hand
    - 9 leg lymphoedema: 7 leg, 2 leg and belly
  - 3 primary lymphoedema, 15 secondary lymphoedema (8 breast cancer, 1 tumour in axilla, 4 gynaecological cancer, 1 prostate cancer, 1 obesitas)

Results – compression garment

Arm lymphoedema (N=9)

- 9 flat-knitted custom-made
- Company:
  - 3 Medi
  - 1 Medi/ Varodem
  - 4 Bauerfeind
  - 1 Jobst
- 8 CCL II and 1 CCL III

Leg lymphoedema (N=9)

- 9 flat-knitted custom-made
- Company:
  - 8 Medi
  - 1 Jobst
- 1 CCL II, 6 CCL III and 2 CCL IV

Results – reliability compression questionnaire

- Wearing information:
  - 7 days a week – ICC: 1.00
  - N=18 daytime
  - 12 hours a day – ICC: 0.88

- A lower score is a better result, are less problems, …

- Easiness of handling:
  - To put on compression device: 3/10 – ICC: 0.72
  - To put off compression device : 2/10 – ICC: 0.98
  - Wearing shoes over compression device : 5/10 – ICC: 0.84
  - Wearing clothes over compression device : 3/10 – ICC: 0.95

Results – reliability compression questionnaire

- Comfort of compression device:
  - Immediate comfort: 3/10 – ICC: 0.56
  - Comfort during daytime: 4/10 – ICC: 0.57
  - Comfort during night: 6/10 – small sample size (N=2)

- Symptoms (without compression):
  - Pain: 2/10 – ICC: 0.55
  - Heaviness: 4/10 – ICC: 0.55
  - Swollen feeling: 3/10 – ICC: 0.51
  - Stiffness: 3/10 – ICC: 0.53
  - Tensed skin: 3/10 – ICC: 0.71
  - Tingling: 2/10 – ICC: 0.84
  - Ulcer secretion: no patients with wound

Results – reliability compression questionnaire

- Side effects of compression garment:
  - Discomfort: 4/10 – ICC: 0.53
  - Warmth: 3/10 – ICC: 0.61
  - Itching: 3/10 – ICC: 0.79
  - Aching: 2/10 – ICC: 0.95
  - Pain: 2/10 – ICC: 0.64
  - Throbbing: 1/10 – 0.96
  - Cramps: 1/10 – 0.33
  - Tender/ sore spots: 3/10 – 0.70
  - Strangulation feeling: 3/10 – 0.91
  - Feeling of sliding: 3/10 – 0.79
  - Bulky: 2/10 – 0.43
  - Claustrophobic complaints: 1/10 – 0.51
  - Impaired mobility ankle/ wrist: 2/10 – 0.76
  - Impaired mobility knee/ elbow: 2/10 – 0.34
  - Impaired mobility hip/ shoulder: 1/10 – small sample size (N=2)

Results – reliability compression questionnaire

- Mental effect
  - Cosmetic acceptable: 4/10 – ICC: 0.83

- General assessment
  - Able to wear: 1/10 – ICC: 0.59
  - Wearing ability: 4/10 – ICC: 0.68
  - Improved daily activities: 4/10 – ICC: 0.48
  - Impaired daily activities: 3/10 – ICC: 0.95

Results – face validity

- Questions understandable:
  - 16 yes, 2 no:
  - bulky, claustrophobic feeling, daily activities
  - Wrong interpretation ‘not applicable’
- Scoring system obvious
  - 18 yes, 0 no
- Questionnaire complete
  - 15 yes, 3 no: more attention for mental complications, skin irritation

Conclusion

- Pilot version of compression questionnaire:
  - Has moderate to high reliability (except for 3 questions)
  - Is not perfectly understandable and complete

  - Have to be corrected to improve reliability and face validity and has to be further examined …
    - Including larger sample size
    - Also other study populations and other compression devices
    - Also other aspects of reliability and validity


Impressed
by you
Twenty-eight portraits of people with
lymphoedema or lipoedema
NLNet
Nederlands Lymfoedeem Netwerk

Patients point of view

- I am ashamed of my stockings, “grand ma feeling” Natascha Assies
- Hate/love affair with my stockings. Need muscles and patience Anthea Molenaar
- Wearing stockings is not a problem when you are 4 years old Lenneke Eijmal
- I refuse to wear skin coloured arm sleeves Ingrid van Dijk
- Wearing shorts and skirts in summer now, I am used to people staring Marise Hoogenboom
- Never get used to wearing stocking every day all my life Stephan Hakkers
- If I get a chance, I will not wear my stockings Anito Ootjers
- Wearing stockings was nonsense I thought, until I met my therapist
- Brigitte van de Watering

Take home message clinicians

- Self-management by patients is not optional but inevitable because clinicians are present for only a fraction of the patient's life, and nearly all outcomes are mediated through patient behaviour. Clinicians who believe they are in control or responsible for a patient's well-being are less able to adopt an approach that acknowledges the central role of the patient in his or her care.

Implementing practical interventions to support chronic illness self-management.
Glasgow RE1, Davis CL, Funnell MM, Beck A.