The challenges of self-management for lymphoedema

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Describe challenges
Overcoming challenges
Primary and secondary lymphoedema

Primary
Genetic

Secondary
Trauma, parasitic disease, surgery, radiation therapy, volcanic dust

Continuum

Primary
Secondary
Why is self-management challenging?

Lymphoedema is **incurable**, requires **lifelong care**, and **psychosocial support**

Lots of competing chronic diseases
What is self-management for lymphoedema?

- Risk reduction
- Skin/nail care
- Elevation/posture
- Exercise
- Self massage
- Deep breathing

- Compression
  - Self bandaging
  - Compression garments
  - Wraps
  - Intermittent pneumatic compression (IPC)

Self-management systematic review - Few high quality papers

(Douglass, Gordon, Graves 2016)
Challenges - Children and adolescents

- Baby and toddler
  - Limited services and experienced clinicians
  - Anxious parents
- School child or teenager
  - Bullying and peer acceptance
  - Body image

- Severe psychosocial consequences
  - Poor self-esteem, social relationships, academic performance and sports participation

Poor research and guidelines for management
(Phillips & Gordon 2014)
Children and adolescents

- Self-management is burdensome
- 6 themes transition to adulthood and self-care
  - Reinforcing abnormality
  - Negotiating uncertainties
  - Vulnerability and caution
  - Disruptive transition
  - Developing resilience
  - Taking responsibility

- Strategies
- Empower young people to advocate for themselves
  - Resources aimed at young adults
- Treatment plans that
  - minimize social restrictions
  - address emotional consequences
  - incorporate the young persons preferences to improve adherence, satisfaction and outcomes

(Hanson et al 2018)
Lymphatic Filariasis LO

15 million people

- Home based care
  - Elevation, hygiene, exercise
- Little/no access to services
  - Traditional healer/standard foot hygiene (Adhikari et al 2104)
- Social stigma - Superstition and social exclusion, loss of opportunity to marry
  - fear of being abandoned
  - fear of transmitting disease to the children
- Poor quality of life
  - Depression, anxiety, worry and stress, low self-esteem
- Inability to engage in paid employment
Lymphatic Filariasis LO

Positive impacts of a community based lymphedema management program (Cassidy 2016)

- Better self-management
- More accepting community
- Improved understanding of the cause of the disease
- Able to hold both a ‘scientific’ and a ‘traditional’ understanding of LF at the same time

- Gender-specific psychosocial support groups to address issues particular to men and women
- Need improved economic opportunities
WHO Lymphatic Filariasis LO

• Policy priorities
  • Scale up LF-related morbidity management programs to reduce the suffering of people affected by LF
  • Assured access to basic self-care education and support services within a certain geographic region

• Recommends integration of services for LF and leprosy
  • Integrating LF affected people into existing leprosy self-help groups in Nepal
  • Would it work? Both groups willing
  • Increase LF LO to knowledge and practice of self-care

(Pryce 2018)
Not only have you had cancer you now have a chronic condition to manage for the rest of your life.....
Self care support needs – BCRL USA

- Lack of social support
  - feeling misunderstood
  - minimization of needs
  - feeling criticized
- Lack of resources for self-care activities
  - lack of both tangible self-care support and self-care supplies
- Self-advocacy by default
  - proactively manage lymphedema complication
  - educate health-care workers
  - feeling marginalized by the healthcare system.

Ridner et al 2016
“Just live with it”
BCRL South Africa

- Not informed of the possibility of developing lymphedema
- Felt let down by the medical professionals they consulted
- No access to support of a knowledgeable therapist
- Could not afford the necessary treatment and the self-care items
- Treatment failure resulted in them feeling exploited and using various treatment options.

(Maree & Beckmann 2016)
Compression garment compliance
BCRL Australia

Compression garments prescribed to 167 women over a 5 year period 22% stopped using them

- Fear and vulnerability = greater use
- Discomfort
- Stable – mild/moderate swelling
- Perceived garments were not effective
- Swelling for greater than 5 years
- Advice re garment use varied across participants

(Longhurst et al 2018)

Is this a problem or simply real self-management?
Costs – BCRL Australia

• Average out-of-pocket financial cost of lymphedema care A$977 per annum
  • Range A$207 to over A$1400 depending on severity of LO

• Compression garments 40% of costs

Boyages et al 2017
Head and neck LO self-Mx

• self-MLD (85 %)
• neck exercise (80 %)
• compression garments (40 %)
• skin care (35 %)

• Exercise
  • general exercise (60 %)
  • swallowing/tongue exercise (20 %)
  • jaw range of motion exercise (15 %)
  • speech/voice therapy exercise (10 %)
  • yoga (5 %)

• assistive devices such as pillow and wedge (25%)

Deng & Murphy 2016
Head and neck self-Mx

Facilitators
- family assistance
- self-motivation
- fear of altered physical appearance
- self-care as part of routine life

Barriers
- time
- difficult to integrate into established routine
- difficulty following directions
- discomfort (compression garment)
- high cost of compression garment
- skin reactions to elastic tape
- lack of motivation and boredom
Head and neck - strategies

- Education prior to cancer treatment
- Support beyond completion of lymphedema therapy
- Text reminders related to self-care
- Information resources need to accommodate various learning styles
  - anatomy and exercise visuals
- Enabling family members’/caregivers’ involvement
- Emphasizing the importance of self-care
The-Optimal-Lymph-Flow health IT system (TOLF)

Patient-centered, web-and-mobile-based educational and behavioral health IT system (Fu et al., 2016)

- Evaluate usability, feasibility, and acceptability people after breast cancer
- Submit symptom report, receive a symptom evaluation in terms of fluid accumulation and recommended self-care strategies immediately
- Avatar technology for training system to assist breast cancer survivors in building self-care skills by visually showing how lymph fluid drain in the lymphatic system when performing lymphatic exercises
Personal challenges

Energy and commitment
Education
Evidence
Cost
Access
Context
Recognition of persons goals
Bigger challenges……

• Society
  • Social isolation, stigma, marginalization

• Professional education
  • Unfortunately, U.S. physicians and health care personnel are woefully unaware of the extent of this condition, and the protocols of its medical treatment…..The sad part of all of this is that the majority of patients suffer their swollen limbs in silence, being told by their physicians that there is nothing to be done, and that they are lucky to be alive.

• Government policy
  • Funding for services and resources
Lymphedema (lim – fa – DEE – ma) is chronic swelling (edema) caused by a build up of fluid (lymph) that occurs when the lymphatic system is either faulty or damaged. There is no cure for lymphedema, but it can be effectively treated.

The Lymphedema Treatment Act (LTA) is a federal bill that aims to improve insurance coverage for the medically necessary, doctor-prescribed compression supplies that are
What does successful self-management look like?

- Integrated into normal life
- Routine
- Recognise the benefit of self-management
- Ownership and empowerment
- Feel in control
- Flexibility in self-management to deal with fluctuations and personal goals
- Self-reliant
  - Able to monitor own condition and adjust self-management
- Their own expert

Jeffs et al 2016
Positive empowerment of health

Empowerment of people with lymphedema to determine their self-care

Informed by readily accessible high quality education

Provide evidence based self-care regime for their context
  Its OK to try something if no harm will be done

Support available from family, trained practitioners, society and government
Only when the person believes the benefits outweigh the challenges will self-management be successful.

Benefits:
- Increased function
- Independence
- Stabilised lymphoedema

Challenges:
- Personal
- Societal
- Government
References


Thank you

Questions/Discussion