

ICF Core Set Development for Lymphoedema in Australia

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Lymphoedema and Cancer

- Lymphoedema is the chronic build up of fluid in the tissue as a result of insufficient lymphatic drainage
- 1/5 of individuals develop lymphoedema of the arm after breast cancer treatment
- Gynaecological, bladder and prostate cancer treatment as well as melanoma treatment are associated with similar risks



Chen, et al (2008). National Breast and Ovarian Cancer Centre (2008)

Lymphoedema Knowledge

- Lack of knowledge among health professionals
 - The large effect that this condition has on individuals is under recognized
- Lack of support services
- Lack of funding



Paskett & Stark (2008); Serie, et al (2013)

Introduction to ICF

The International Classification of Functioning, Disability and Health (ICF) is a WHO framework for measuring functioning and disability associated with a specific condition at the individual and population level



World Health Organization (2013)

ICF Categories



ICF Core Set Purpose

- To help optimize the health care services that people with lymphoedema receive by
 - Providing health care workers with an understanding of the affect of lymphoedema
 - Informing service providers and policy makers of the services required by individuals with lymphoedema



ICF Core Set Development



Aim

To identify the most important factors influencing functioning of individuals with lymphoedema in order to help direct the formation of an ICF Core Set for this disorder.



Study Design

- Multi-center cross-sectional study
- In person, conversation based interview
- Answered 102 questions from the ICF tool:
 - 0 – NO problem
 - 1 – MILD problem
 - 2 – MODERATE problem
 - 3 – SEVERE problem
 - 4 – COMPLETE problem
 - 8 – Not specified
 - 9 – Not applicable
 - C – COMORBIDITY
- The study is ongoing in South Australia



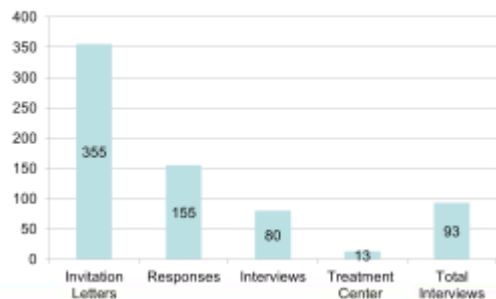
Research Team in Adelaide, Australia



Back Row: David Hancock, Anna Herbert, David Warncken and Neil Piller
 Front Row: Bridget Lloyd-Fox, Rebecca Walley, Shannon Vanderstelt, Malou van Zanen
 Absent: Kate Bryson, Kathleen Wang



Recruitment Process



Participants

Total Number of Participants	93
Location of Lymphoedema	Arm 38 (41%) Leg 43 (46%) Midline 1 (1.1%) Combination 11 (12%)
Gender	Females 80 (86%) Males 13 (14%)
Median Age	60 years of age
Marital Status	Married 51 (54.8%) Other 42 (45.2%)
Patients Living Alone	24 (26%)
Post-Secondary Education	50 (57%)
Occupation	Paid-Employment 27 (29%) Non-paid Employment 54 (58.1%) Unemployed for Health Reasons 12 (12.9%)
Median Time Since Diagnosis with Lymphoedema	8 years
Cause of Lymphoedema	Primary 3 (3.2%) Secondary 74 (80%) Other 16 (17%)

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Results

Body Functions

- Leg Participants:
 - Repair Functions of Skin 70.5% (48.0%)
 - Mobility of Joint 70.0% (52.6%)
 - Protective Functions of Skin 63.4% (37.5%)
 - Sensation of Pain 62.5% (31.8%)
 - Immunological System Function 61.5% (25.0%)
 - Muscle Power Functions 55.0% (14.3%)
- Arm Participants:
 - Sensation of pain 58.3% (16.7%)
 - Protective functions of the skin 55.3% (15.0%)
 - Repair functions of the skin 54.1% (19.0%)
 - Immunological system functions 51.7% (12.5%)

Activity Limitations

- Leg Participants:
 - Walking 75.7% (52.6%)
 - Changing Basic Body Position 71.1% (35.3%)
 - Moving Around in Different Locations 56.8% (30.4%)
 - Recreation and Leisure 54.8% (34.5%)
 - Maintaining a Body Position 53.8% (35.7%)
- Arm Participants:
 - Lifting and carrying objects 77.1% (52.9%)
 - Hand and arm use 63.9% (35.0%)
 - Carrying out daily routine 51.4% (5.6%)
 - House Chores 50.0% (15.0%)

Leg vs Arm Participants

- Those with **leg** lymphoedema were found to have significantly more challenges in regards to:
 - Walking
 - Changing body position
 - Self care
 - Dressing
 - Emotional function
 - Energy and drive
 - Sensation to temperature, pain and vibration; thermoregulatory functions
 - Immunological functions; repair and protective functions of the skin

Leg vs Arm Participants

- **Arm** lymphoedema participants were found to have significantly more challenges in regards to:
 - Lifting and carrying objects
 - Economic self sufficiency
 - Carrying out daily routine



Environmental and Personal Factors (Facilitator/Barrier)

- | | |
|---|---------|
| • Health Professionals | (60/21) |
| • Immediate family | (72/4) |
| • Climate | (3/73) |
| • Health services, systems and policies | (49/26) |
| • Societal Attitudes | (5/27) |



Conclusion

- There is a lack of health professional knowledge, support services and funding available for people with lymphoedema
- We hope that the findings from this research will help:
 - Gain recognition of lymphoedema as a chronic condition that has significant effects on quality of life
 - Initiate policy changes that will allow lymphoedema sufferers to have access to more financial and social support services



Acknowledgements

- Lymphoedema Research Unit:
 - Professor Neil Piller
 - Malou van Zanten
- Lymphoedema and Laser Therapy Clinic
 - Sharon Tilley (Physiotherapist)
- Others
 - Peter Viehoff (Trial Coordinator)
 - Froukje Potijk (Physiotherapist in The Netherlands)



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