Finnane, Anna, Hayes, Sandra C., Obermair, Andreas, & Janda, Monika (2011) Quality of life of women with lower-limb lymphedema following gynecological cancer. *Expert Review of Pharmacoeconomics and Outcomes Research*, *11*(3), pp. 287-297.

http://dx.doi.org/10.1586/erp.11.30

Table 1. Characteristics of studies assessing quality of life of women with lymphoedema following gynaecological cancers

Study	Design and Methods	Sample Size	Age of Participants	Recruitment method and sampling frame	Time since cancer treatment or time since diagnosis of LLL
Qualitative Studies					
Appollo (2007)	Case Study	1 endometrial cancer patient	56 years	Gynecologic Oncology department, New York, US	Reported swelling in leg approximately 6 months after completing cancer treatment
Frid et al. (2006)	Qualitative study – semi-structured interviews. Phenomenographic approach used for data analysis.	13 patients with cancer related LLL (2 cervical cancer) diagnosed by physician	47-70 years	Maximum variation sampling strategy (age, gender, diagnosis, care environment, also locality, severity and cause of LE) from three clinics in Stockholm, Sweden	LLL present for 2 weeks - 5 years
Janda et al. (2004)	Qualitative study – semi-structured interviews.	15 vulvar cancer patients LE reported as a symptom – self-report	52-85 years	Recruited from Qld Centre for Gynaecological Cancer, Australia (method of recruitment not described)	Time since surgery – 2 weeks to 39 months
Ryan et al. (2003)	Qualitative study – structured interviews. Content analysis applied to interview data.	82 women with clinically diagnosed LE	Age not reported	Contact made with women through gynaecological cancer database (New South Wales, Australia) - women invited to participate.	All had surgery within last 5 years, but no timing reported
Quantitative Descriptive Studies					
Beesley et al. (2007) **Beesley et al. (2008)**	Quantitative cross-sectional mailed survey.	802 women 3 months-5 years following gynaecological cancer 81 had diagnosed LLL Vulvar cancer highest (36%) prevalence of diagnosed LLL 110 had undiagnosed lower limb swelling	Total age range not reported but 74% of sample over 50 years.	Survey sent to patients listed on Qld Gynaecological Cancer Registry, Australia.	3 months - 5 years
Bergmark et al. (2006)	Quantitative cross-sectional mailed survey.	256 women with history of cervical cancer, 350 controls (general population) LE symptoms self reported	Cases age -26-74 years (mean, 48 years)	Survey sent to all patients with early stage cervical cancer at seven departments of gynaecological oncology in Sweden. Control group of 489 women randomly selected from Swedish population registry.	Approximately 5 years after treatment for cervical cancer

Quantitative Intervention Studies					
Katz et al. (2010)	Pre-post intervention study evaluating progressive weight training	10 participants, 6 with gynaecological cancers Either had clinically diagnosed LLL or >6% discrepancy between limb volumes.	50-71 years (mean, 60.1 years)	Patients of University of Pennsylvania contacted who were known to have cancer-related LLL.	Completed treatment for cancer at least 1 year prior. Mean 13 years ± 14 years.
Kim et al. (2008)	Pre-post intervention study evaluating complex decongestive physiotherapy	57 participants Range of gynaecological cancers	31-71 years (mean, 48 years)	Physician-referred for LE treatment at one of three physical therapy clinics in South Korea.	Completed treatment for cancer 0.3 - 4.8 years, mean 2.4 post-treatment.
Sawan et al. (2009)	Pilot randomised, controlled trial of prophylactic compression garments	14 participants (7 treatment group, 7 controls) all with vulvar cancer	41-87 years (mean, 71.5 years)	Gynaecologic Oncology Centre (Manchester, UK) – all referrals of vulvar cancer contacted and invited to participate.	Pre-op – 6 months post surgery

LE: Lymphedema; LLL: Lower-limb lymphedema.

Table 2. Results of studies assessing QoL in patients with LLL following gynaecological cancers

Study	QoL Measurement tool	Results	Conclusions
Qualitative Studies			
Appollo (2007)	Qualitative description of patient	Patient described heavy, achy feeling in leg. Swelling increased when sitting (in church or teaching piano lessons). Modification of clothing – long skirts and dresses to cover swollen leg. Lost desire to be in public. Slower pace when walking dog. Joined cancer support group – sharing difficulties helped to cope. Prescribed pain and sleep medications.	Individual assessment critical for pain, sleep disturbance, changes to lifestyle, providing appropriate and sufficient information to patients.
Frid et al. (2006)	Semi-structured interviews	Physical function – dependence on others for daily activities. Psychological function – hope and worry, irritation, fear, impact on body image. Social impact – positive and negative experiences in interactions with other people. Pity from some people and lack of understanding from others. Information needs – participants wanted more thorough examinations and more knowledge spread about lymphoedema.	Both positive and negative experiences - some people experienced LLL as minor problem in context of impeding death. Others wanted to make the most of the time left, so LLL caused limitations and impediments on daily life.
Janda et al. (2004)	Semi-structured interviews	Various reductions in physical activity level following LLL Either not or rarely sexually active, or severe difficulties with sexuality/intimacy (5 patients, all under 65 years) Difficulties with social relations and employment	LLL found to be most frequent symptom following vulvar cancer. LLL can be tiring and energy reducing – requires constant attention in terms of treatment. LLL can reduce ability to work, perform household duties and socialise. Negative impact on body image and self-esteem
Ryan et al. (2003)	Structured interviews	Financial burden – 27% reported financial burden from LLL-related expenses (eg. Treatment). Changes to clothing – 38% required shoe alterations, 33% increased clothing size, 27% changed type of clothing worn (eg. Loose fitting)	LLL altered women’s daily activities and had significant psychological, social and financial implications.

		Changes to activities – 51% altered everyday activities, 20% unable to walk long distances, 13% change in occupation or restrictions in job opportunities, 6% found shopping very difficult. Also changes in personal/social relationships and loss of intimacy with partners.	
Quantitative Descriptive Studies			
Beesley et al. (2007)	Unvalidated LE questionnaire and SCNS-SF34	30% mild difficulty, 26% moderate difficulty and 5% severe difficulty performing daily tasks 25% had mod/high unmet need for LE specific information and 20% had mod/high unmet needs in pain/symptom management.	Women with diagnosed lymphoedema had higher odds of unmet needs in all four domains compared with those without lymphoedema. Patients need more info about LLL sooner after cancer treatment.
Beesley et al. (2008)	Unvalidated LE questionnaire and SCNS-SF34	Those with LLL had higher odds of psychological (OR=5.58, 95%CI=2.26-13.81), physical or daily living (OR=4.55, 95%CI=1.75-11.83), sexual needs (OR=3.49, 95%CI=1.31-9.30) and health system/information needs (OR=2.55, 95%CI=1.00-6.52) than those without LLL (adjusted results).	Need to be aware of, and to be treated with, most up-to-date treatment (suggested complex physical therapy and benzopyrones). Need access to therapists trained in lymphoedema massage and exercises.
Bergmark et al. (2006)	Unvalidated questionnaire	19% of cases reported swollen legs and/or abdomen, always or almost always 12% of cases reported heavy legs and/or abdomen, always or almost always 51% of women with self-reported lymphoedema symptoms following treatment for cervical cancer reported finding the symptoms moderately or much distressful.	High levels of distress should be acknowledged with detailed information before and after cancer treatment, early diagnosis efforts and early intervention plans.
Quantitative Intervention Trials			
Katz et al. (2010)	Validated QoL Tool, SF-36, LLL survey (adapted from validated ULL survey) measured physical mobility and pain	No significant changes in QoL. Lymphoedema severity improved from 1.1-0.8 over first 2 months (on scale from 0-3, p=0.02) and improvement was largely maintained at 5 months.	Improvements in physical function and strength, but not QoL.

Kim & Park (2008)	Validated QoL Tool, SF-36	Improvements of 5-7 points in QoL scores for physical functioning, social functioning, role-physical, mental health and general health (all statistically significant, unadjusted results) between baseline and follow up.	Improvements in QoL suggest Complex decongestive physiotherapy is beneficial for women with LLL following gyneaecological cancer.
Sawan et al. (2009)	Validated QoL Tool, NHP-1 completed preoperatively and at 3 and 6 months postoperatively	No differences in the NHP-1 scores between control and treatment groups at any time point. Scores in emotional reaction domain decreased over time 2.4 pre-op to 1.5 six months post-op (p=0.02).	Compression stockings did not worsen quality of life, and improved symptoms and efficacy to reduce leg swelling.

LE: Lymphedema; LLL: Lower-limb lymphedema; NHP-1: Nottingham Health Profile, part 1; OR: Odds ratio; QoL: Quality of life; SCNS-SF34: Standardized Supportive Care Needs Survey Short Form; SF-36: Medical Outcomes Study 36-item Short-Form Health Survey; ULL: Upper-limb lymphedema.

Table 3. Adverse effects of lower-limb lymphoedema on quality of life and concerns associated with quality of life, as reported by qualitative and quantitative studies

Impact	Qualitative	Quantitative Descriptive	Quantitative Intervention
Physical Concerns			
Limb-specific symptoms: Swelling, visible lumps, puffiness, redness, heaviness, hardness, heat, tenderness, pins and needles, aching, tightness, sharp pain, throbbing sensation	●	●	●
Fatigue	●		●
Daily Life Concerns			
Avoidance of triggers: cellulitis, falls, ascitic tap, sunburn, injection to affected limb, insect bites, heat exposure (sitting close to radiator, hot weather, hot spa, sauna)	●	●	
Difficulty performing daily tasks	●	●	
Challenges finding suitable clothing/footwear	●		
Difficulty being confined in one position for long periods of time (eg. sitting in work role or long-distance travel)	●	●	
Psychological and Emotional Concerns			
Worry about progression of the condition	●		
Distress		●	
Poor body-image	●		
Low self-esteem	●		
Avoidant coping strategies	●		
Sexuality Concerns			
Difficulties with sexuality and intimacy	●		
Social Concerns			
Limit social activities	●		
Embarrassment	●		
Lack of understanding regarding lymphoedema from others	●		
Concerns Related to Lymphoedema Treatment			
Effect of treatment on overall QoL			●
Unmet psychological needs		●	
Unmet sexual needs		●	
Inadequate symptom management	●	●	
Difficulty completing treatment without help from another person	●		●
Lack of lymphoedema specific information	●	●	
Lack of thorough examinations	●		
Financial burden of treatment	●		