

Lets talk genital lymphedema

Improving ways to diagnose and treat the taboo area

By Shelley DiCecco

Editors Note: The author of this article is available to assist any HCP with evaluation or treatment questions via email at ShelleyDiCecco@LymphEd.com. The author is conducting a study pertaining to the education on and comfort level with treating genital lymphedema. HCPs may participate in the study by scanning the following QR image.



SCAN ME

References

1. Bolt, R.J., Peelen, W., Nikkels, P.G.J. and De Jong, T.P.V.M., 1998. Congenital lymphoedema of the genitalia. *European journal of pediatrics*, 157(11), pp.943-946.
2. Schook, C.C., Mulliken, J.B., Fishman, S.J., Grant, F.D., Zurakowski, D. and Greene, A.K., 2011. Primary lymphedema: clinical features and management in 138 pediatric patients. *Plastic and reconstructive surgery*, 127(6), pp.2419-2431.
3. Wananukul, S. and Jittitaworn, S., 2005. Primary Congenital Lymphedema Involving All Limbs and Genitalia. *JOURNAL-MEDICAL ASSOCIATION OF THAILAND*, 88(12), p.1958.
4. Hall, A., 2019. *Atlas of Male Genital Dermatology*. Springer International Publishing.
5. Noble-Jones, R., Thomas, M.J., Davies, L. and Morgan, K., 2019. Are you handling genital oedema confidently? *British journal of community nursing*, 24(Sup10), pp.S19-S22.
6. Lee, B.B., Rockson, S.G. and Bergan, J. eds., 2018. *Lymphedema: a concise compendium of theory and practice*. Springer.
7. Yamamoto, T., Yamamoto, N., Yoshimatsu, H., Hayami, S., Narushima, M. and Koshima, I., 2013. Indocyanine green lymphography for evaluation of genital lymphedema in secondary lower extremity lymphedema patients. *Journal of Vascular Surgery: Venous and Lymphatic Disorders*, 1(4), pp.400-405.
8. Schook, C.C., Kulungowski, A.M., Greene, A.K. and Fishman, S.J., 2014. Male genital lymphedema: clinical features and management in 25 pediatric patients. *Journal of pediatric surgery*, 49(11), pp.1647-1651.
9. Alexakis, C., Gordon, K., Mellor, R., Chong, H., Mortimer, P. and Pollok, R., 2017. Ano-genital granulomatosis and Crohn's disease: a case series of males presenting with genital lymphoedema. *Journal of Crohn's and Colitis*, 11(4), pp.454-459.
10. Lang, E.M., Munder, B.I., Andree, C., Foeldi, E., Felmerer, G. and Stark, G.B., 2006. A modified therapeutic option for a long-lasting success in the treatment of genital lymphedema. *European Journal of Plastic Surgery*, 29(1), pp.13-18.
11. Torio-Padron, N., Stark, G.B., Földi, E. and Simunovic, F., 2015. Treatment of male genital lymphedema: an integrated concept. *Journal of Plastic, Reconstructive & Aesthetic Surgery*, 68(2), pp.262-268.

12. Varghese, S.A., 2021. Secondary lymphedema: Pathogenesis. *Journal of Skin and Sexually Transmitted Diseases*, 3(1), pp.7-15.
13. Coelho, M., Oliveira, T. and Fernandes, R., 2013. Biochemistry of adipose tissue: an endocrine organ. *Archives of medical science: AMS*, 9(2), p.191.
14. Cooper, P.O., Haas, M.R. and Shook, B.A., 2021. Dermal drivers of injury-induced inflammation: Contribution of adipocytes and fibroblasts. *International journal of molecular sciences*, 22(4), p.1933.
15. Zampell, J.C., Aschen, S., Weitman, E.S., Yan, A., Elhadad, S., Andrade, M.D.B. and Mehrara, B.J., 2012. Regulation of adipogenesis by lymphatic fluid stasis part I: adipogenesis, fibrosis, and inflammation. *Plastic and reconstructive surgery*, 129(4), p.825.
16. Aschen, S., Zampell, J.C., Elhadad, S., Weitman, E., Andrade, M.D.B. and Mehrara, B.J., 2012. Regulation of adipogenesis by lymphatic fluid stasis part II: expression of adipose differentiation genes. *Plastic and reconstructive surgery*, 129(4), p.838.
17. Mehrara, B.J. and Greene, A.K., 2014. Lymphedema and obesity: is there a link? *Plastic and reconstructive surgery*, 134(1), p.154e.
18. Zaleska, M.T. and Olszewski, W.L., 2017. Serum immune proteins in limb lymphedema reflecting tissue processes caused by lymph stasis and chronic dermato-lympho-angio-adenitis (Cellulitis). *Lymphatic research and biology*, 15(3), pp.246-251.
19. Tashiro, K., Feng, J., Wu, S.H., Mashiko, T., Kanayama, K., Narushima, M., Uda, H., Miyamoto, S., Koshima, I. and Yoshimura, K., 2017. Pathological changes of adipose tissue in secondary lymphoedema. *British Journal of Dermatology*, 177(1), pp.158-167.
20. Noble-Jones, R., Thomas, M.J. and Bose, P., 2019. The Lymphoedema Genitourinary Cancer Questionnaire in urology follow-up clinics. *International Journal of Urological Nursing*, 13(1), pp.5-12.
21. Hara, H. and Mihara, M., 2017. Indocyanine green lymphographic and lymphoscintigraphic findings in genital lymphedema—genital pathway score. *Lymphatic research and biology*, 15(4), pp.356-359.
22. Ha, K.J., Lee, S.Y., Lee, H. and Choi, S.J., 2017. Synergistic effects of proprioceptive neuromuscular facilitation and manual lymphatic drainage in patients with mastectomy-related lymphedema. *Frontiers in physiology*, 8, p.959.
23. Ha, K. and Choi, S., 2014. The effect of a PNF technique program after mastectomy on lymphedema patients' depression and anxiety. *Journal of physical therapy science*, 26(7), pp.1065-1067.
24. Drewes, R.C., Hedrick, M.S., Hillman, S.S. and Withers, P.C., 2007. Unique role of skeletal muscle contraction in vertical lymph movement in anurans. *Journal of Experimental Biology*, 210(22), pp.3931-3939.
25. Havas, E., Parviainen, T., Vuorela, J., Toivanen, J., Nikula, T. and Vihko, V., 1997. Lymph flow dynamics in exercising human skeletal muscle as detected by scintigraphy. *The Journal of physiology*, 504(1), pp.233-239.
26. ROSS, J.H., Kay, R., Yetman, R.J. and Angermeier, K., 1998. Primary lymphedema of the genitalia in children and adolescents. *The Journal of urology*, 160(4), pp.1485-1489.
27. Boris, M., Weindorf, S. and Lasinski, B.B., 1998. The risk of genital edema after external pump compression for lower limb lymphedema. *Lymphology*, 31(1), pp.15-20.

Lower Limb and Genital Lymphedema Questionnaire for Women (LLGLQw)

Name, contact details and DoB or hospital number:

Self-completion questionnaire for women who have lower limb edema and may have genital area oedema / Lymphedema.

Today's date: _____

Swelling in the legs / genitals can be quite normal for a few weeks after some treatments or with some chronic conditions. Sometimes these can be difficult to describe but this questionnaire may help. Please complete the questions below to help us give you the appropriate advice and care.

Personal Impact		Not at all (or not relevant) 0	A little bit 1	Quite a bit 2	Very much 3
Over the last month how has the swelling affected your daily activities:					
	<i>(for example)</i>		✓		
I have swelling:	in my leg(s)				
	in my genitals				
If you feel you have <u>no</u> swelling at all you do not need to complete the rest of this questionnaire.					
The swelling is worse by the end of the day					
The swelling is affecting:	which clothes/shoes I can wear				
	my sitting				
	getting in/out of bed				
	my walking				
	urination				
The skin around the swollen area:	my sexual function				
	feels tight				
	has changed colour				
	feels different				
The swelling gives me discomfort:	feels wet/cold				
	in my leg(s)				
I need to take painkillers for the discomfort	in my genitals				
<i>Please continue overleaf/next page.</i>					
<i>Therapist to calculate after completion</i>	Score for Personal Impact Section (score above / 48) x 100= % limited				

If you have swelling of your legs or genitals please show in these picture where you feel it is, by shading like this:



Name, contact details and DoB or hospital number:



Please tick any relevant		√
	I feel swollen inside	
	The inside is sticking out	
	The outside is swollen	
	Inside and outside feels swollen	

On average this week how severe has the swelling been?

	0 =No swelling	1 = a little bit	2 = quite a bit	3 = very swollen
Legs				
Genitals				

Is there anything else you would like to tell us about how this is affecting you physically or emotionally?

	Yes	No
During the last year, have you needed antibiotics for infections (cellulitis) in your leg(s) or genitals?		
Have you been offered any advice or treatment for the things you have identified here?		
Would you like to discuss this with us?		
<i>Health professional to complete:</i> Name of health professional _____ has discussed the contents of this form with the patient Signed: _____ Date: _____		

Patient/client (name, address, contact details).

Lower Limb and Genital Lymphedema Questionnaire for Men (LLGLQ)


Self-completion questionnaire for men who have lower limb edema and may also have genital area edema / lymphedema.

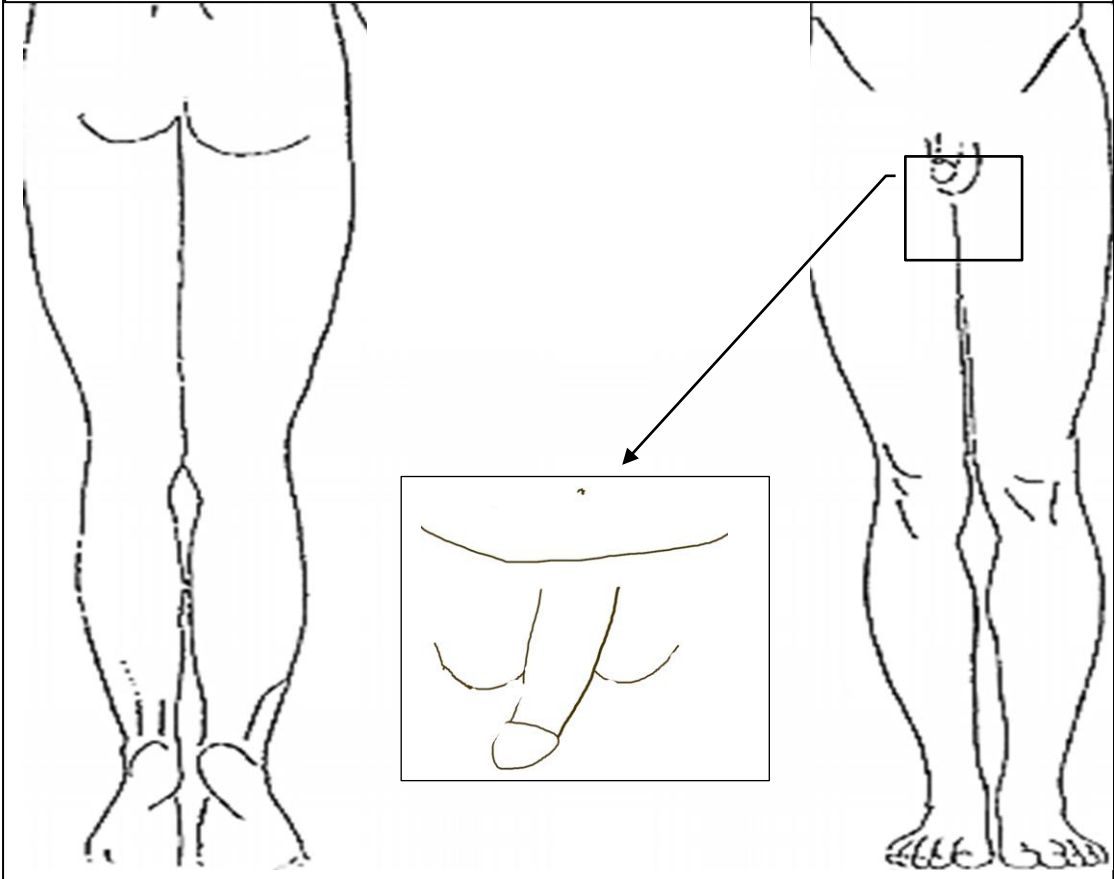
Today's date: _____

Swelling in the legs / genitals can be quite normal for a few weeks after some treatments or with some chronic conditions. Sometimes these can be difficult to describe but this questionnaire may help. Please complete the questions below to help us give you the appropriate advice and care.

Personal impact due to changes in your lower body		Not at all (or not relevant) 0	A little bit 1	Quite a bit 2	Very much 3
			✓		
<i>(for example)</i>					
I have swelling:	in my leg(s)				
	in my genitals				
If you feel you have <u>no</u> swelling at all you do not need to complete the rest of this questionnaire.					
The swelling is noticeably more by the end of the day					
The swelling is affecting:	which clothes/shoes I can wear				
	my sitting				
	getting in/out of bed				
	my walking				
	urination				
	my sexual function				
The skin around the swollen area:	feels tight				
	has changed color				
	feels different				
	feels wet/cold				
The swelling gives me discomfort:	in my leg(s)				
	in my genitals				
I need to take painkillers for the discomfort					
Score for Personal Impact Section (score above / 48) x 100= % limited					
Questions on history of your symptoms					
During the last year have you needed antibiotics for infections (cellulitis) in your leg(s) or genitals?				Yes	No
If yes, how many times has this happened?					
Can you briefly describe what started your swelling?					

Patient/client (name, address, contact details).

If you have swelling of your legs or genitals please show in this picture where it is, by shading like this: 



On average this week how severe has the swelling been?			
0 = No swelling	1 = a little bit	2 = quite a bit	3 = very swollen

Is there anything else you would like to tell us about how this is affecting you physically or emotionally?

	Yes	No
Have you been offered any advice or treatment for lymphedema (swelling)?		
Would you like any information or advice?		
For completion by doctor/therapist:		
Referred to lymphedema service for assessment?		

First endowed Research Chair in lymphatic disorders in Canada arrives at the University of Alberta

By Spencer Gibson

References

1. Caligaris-Cappio, F. & Hamblin, T. J. B-cell chronic lymphocytic leukemia: a bird of a different feather. *J Clin Oncol* 17, 399–408 (1999).
2. Oliver, G., Kipnis, J., Randolph, G. J. & Harvey, N. L. The Lymphatic Vasculature in the 21st Century: Novel Functional Roles in Homeostasis and Disease. *Cell* 182, 270–296 (2020).
3. Tandra, P., Kallam, A. & Krishnamurthy, J. Identification and Management of Lymphedema in Patients With Breast Cancer. *J Oncol Pract* 15, JOP.18.00141 (2019).

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Kinect-enhanced lymphatic exercises

Reducing lymphatic pain, swelling, and lymph fluid level

By Mei Fu

This article is a synopsis of an innovative feasibility study conducted by our research team and published in the journal Integrative Cancer Therapies, titled “The Effects of Kinect-Enhanced Lymphatic Exercise Intervention on Lymphatic Pain, Swelling, and Lymph Fluid Level.” View the free open full article: <https://pubmed.ncbi.nlm.nih.gov/34160294/>.

This study was registered in ClinicalTrials.gov with US ClinicalTrials.gov Identifier:NCT03999177. This study was supported by the National Institute of Health /National Science Foundation /National Cancer Institute (1R01CA214085-01) with Drs. Mei R Fu and Yao Wang as the multiple principal investigators.

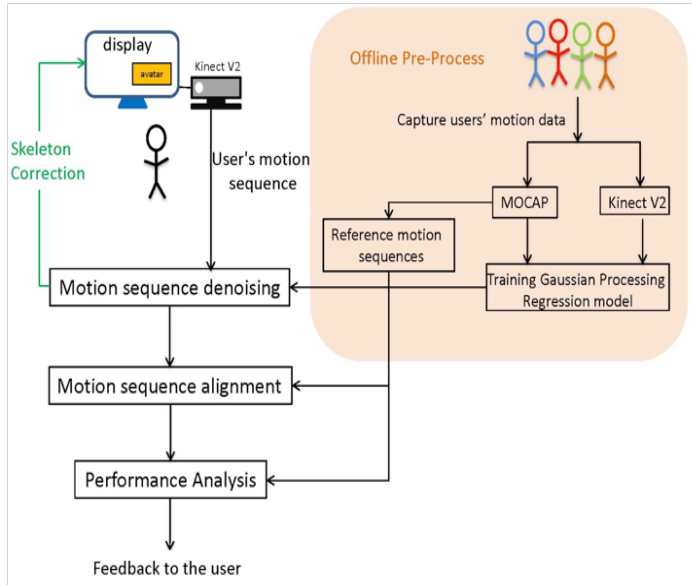
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Fu, M.R., McTernan, M.L., Qiu, J.M., Ko, E., Yazicioglu, S., Axrelrod, D., Guth, A., Fan, Z., Sang, A., Miaskowski, C., & Wang, Y. (2021). The effects of Kinect-enhanced lymphatic exercise intervention on lymphatic pain, swelling, and lymph fluid level. Integrative Cancer Therapies, 20:15347354211026757 . DOI: 10.1177/15347354211026757 PMID:34160294; PMCID: PMC 8226364

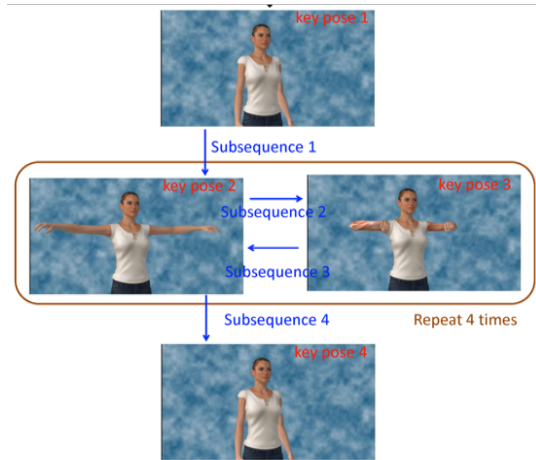
FOLLOWING ARE THREE FIGURES WHICH WERE NOT INCLUDED IN PATHWAYS ARTICLE:

Figure 1. Kinect-enhanced lymphatic exercise intervention

Overall system



Motion sequence alignment



Prototype System User interface

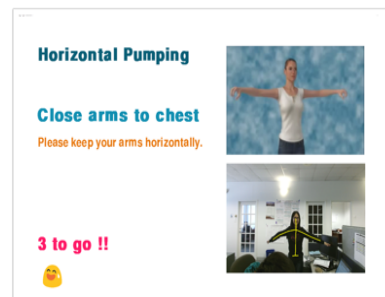


Figure 2. Patient flow chart

