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Lymphedema Patients and Their Limb Care; How Much Do They Know? How Compliant Are They?

Running Title: Lymphedema Patients Their Knowledge and Compliance.

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Abstract

Introduction:
The main objective of this study was to identify the level of knowledge and to asses the compliance and the factors that influence limb care in lymphedema patients in Sri Lanka. Currently only limited studies have been conducted regarding this important subject.
Materials and Methods:
The study was a descriptive cross sectional study. A cluster sampling method was used. 100 patients with lymphedema were selected from the Infectious Disease Hospital and from selected clinics in Colombo, Sri Lanka, Data was collected via Interviewer Administered Questionnaire. Data analysis was done using the SPSS program. Knowledge was graded as high and low according to the mean (=70) and Compliance was graded as high and low according to the mean (=70).
Results:
The knowledge in patients regarding lymphedema and its limb care was poor. Furthermore, on assessment of compliance majority of the patients had high compliance but lacked proper knowledge. There was a significant association between high compliance and having received previous instructions.
Conclusions:

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Health programs regarding lymphedema are much needed to reduce the stigma regarding lymphedema and to ascertain that if diagnosed early and treated adequately with proper limb care lymphedema is a reversible condition.
Therefore, the healthcare professionals in all hospitals should focus on delivering high quality information about lymphedema and its management to individuals with lymphedema.

Keywords: lymphedema; knowledge; compliance; limb care

Introduction

Lymphedema is an abnormal collection of protein rich fluid in the interstitium resulting from obstruction of lymphatic drainage. Lymphatic obstruction causes an increase in the protein content of the extravascular tissue with subsequent retention of water and swelling of the soft tissue- pitting edema. In later stages the extravascular protein stimulates proliferation of fibroblasts, organization of the fluid and development of non-pitting swelling of the affected extremity. Although etiology determines the classification of lymphedema as either primary or secondary, it rarely impacts the choice of treatment (1).

According to the severity of the disease Lymphedema can be staged. The most common method of staging was defined by the fifth WHO Expert Committee of Filariasis (WHO 2014). Stage 0 which is latent, stage 1 (Spontaneously reversible) when the tissue is at the pitting oedema stage. Stage 2 (Spontaneously irreversible) the tissue now has a spongy consistency and is considered non-pitting. Stage 3 (Lymphostatic elephantiasis); at this stage the swelling is irreversible and usually the affected area is very large. The tissue is hard, fibrotic and unresponsive.

Insight into the etiology and natural history of lymphedema has improved, but there is no cure (2). Therapy for lymphedema should be started as early as possible before extensive, irreversible fibrosclerotic changes occur in the interstitium (1).

Lymphoedema arising for reasons other than cancer treatment is much more prevalent than generally perceived, yet resources for treatment are mainly cancer-based, leading to inequalities of care (3). Primary lymphedema can be managed effectively as a form of chronic lymphedema by a sequenced and targeted treatment and management program based around a combination of Decongestive Lymphatic Therapy (DLT) with compression therapy, when the latter is desired as an adjunct to DLT. Treatment in the maintenance phase should include compression garments, self-management, including self-massage, meticulous personal hygiene and skincare, in addition to lymph transport-promoting exercises and activities, and, if desired, pneumatic compression therapy applied at home. When conservative treatment fails, or gives sub-optimal outcomes, the management of primary lymphedema can be improved, where appropriate, with the proper addition of surgical interventions, either reconstructive or ablative. These two surgical therapies can be more effective when fully integrated with manual lymphatic drainage (MLD)-based DLT postoperatively. Compliance with a long-term commitment to MLD/DLT and particularly compression postoperatively is a critical factor in determining the success of any new treatment strategy involving either reconstructive or palliative surgery. The future of management of

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primary lymphedema has never been brighter with the new prospect of gene-and perhaps stem-cell oriented management (4).

The major adverse clinical outcomes of poor compliance to limb care include ulceration due to lymphangiectasia, lymphorrhorea, inflammation and pustule formation, skin maceration, infection, papillomatosis and hyperkeratosis. These sequential changes give rise to ulcers in the overlying skin because adequate perfusion is impaired (5). Other complications include functional impairment with significant effects on patients' quality of life, a reduced ability to work and carry out normal daily activities, and reduced self-confidence. Patients are also at increased risk of recurrent cellulitis (6)

The objectives of this study would be to identify the level of knowledge about lymphedema, compliance to limb care and the factors that influence the compliance among patients with lymphedema in selected clinics in Colombo, Sri Lanka.

Materials and Methods

The study was a descriptive cross sectional study, using 100 patients with lymphedema in selected clinics in Colombo and from the Institute of Infectious Diseases, Kollonawa, Sri Lanka. Participants were adults aged 18 years and above, identified with the help of health care workers who provided care to these patients. Participants were excluded if they were pregnant or suffering from another debilitating disease.

A cluster sampling method was used and data collection was done via Interviewer Administered Questionnaire. The study team distributed the questionnaires among the study participants and was available at all times for any clarifications or questions arising from the participants. The participation in this study was entirely voluntary. The questionnaire was of 2 parts, 1stpart was to assess knowledge among the patients regarding lymphedema and limb care and the 2ndpart was to assess the compliance to their limb care.

Data analysis was done using spreadsheet management software and statistical package for social sciences programme. Each question assessing knowledge and compliance was given a score and from the total score for knowledge and total score for compliance, their mean and standard deviation was calculated. Knowledge was graded as high and low according to the mean knowledge of 70. Compliance was graded as high and low according to the mean compliance of 70.

Ehical approval for this study was given by the Ethics Review Committee of Faculty of Medical Sciences, University of Sri Jayewardenepura, Sri Lanka. All participants gave informed consent prior to their participation in the study.

Results.

The mean age of the participants was 54.57 years. Sixty three (63%) percent were females, 79% were not educated up to a higher level, 76% were married and 63% were employed. Majority did not have any co-morbidities affecting them. Ninety four (94%) percent had received instructions

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on limb care mostly from medical sources. There was no significant association between socio demographic factors and high compliance. However, there was a significant association with high compliance and having received previous instructions. Sixty nine (69%) of the participants were in the reversible stages of lymphedema, and 73% had been seeking treatment for less than a year.

Taking into consideration compliance to limb care among the 100 patients with lymphedema, 59% had high compliance. However only 23% of the patients had high knowledge regarding the care of their limbs affected by lymphedema (Table 1). Among the 59% of patients with high compliance only 27.1% had high knowledge regarding lymphedema, while 72.9% of patients with high compliance had low knowledge. Although most patients were compliant to their limb care their knowledge was poor and a statistically significant association was not found between knowledge and compliance (p= 0.240383) (Table 2).

Considering the patient factors of the study population, 64% did not have any co-morbidities, and among the 36% who had co-morbidities, the daily activities such as limb care was interfered in only 28%. However there was no significant association between interference of co-morbidities to compliance of limb care (p=0.830). Furthermore being aged 50 years or below is 0.589 times (95% CI=0.256-1.358) more likely to cause high compliance. Similar results were seen with being male (OR = 0.677; 95%CI=0.293-1.565) having an education up to or below grade 10 (OR=0.908; 95%CI=0.343-2.404) and being unmarried (OR=0.509; 95%CI=0.189-1.368).

Having a co-morbidity is 0.872 times more likely to cause high compliance than not having a co-morbidity, and an interference caused to limb care due to these co morbidities are 0.906 more than no interference in causing high compliance. However not receiving instructions on limb care has a risk of 1.236 more than receiving instructions on limb care in causing high compliance.

Ninety four (94%) percent of patients with lymphedema had received instructions on limb care. The main source of instructions was from medical personnel (76%) while the rest received instructions regarding limb care from non-medical sources such as media, family and friends.

With regard to socio demographic and patient factors that can be associated with compliance, age had no significant association with high or low compliance p= 0.217, and neither did other socio demographic factors such as gender (p=0.361), patient's education level (p=0.846), occupation (p=0.727) and marital status (p=0.176)

Importantly, having received previous instructions on limb care regarding a lymphoedema affected limb, had a significant association with compliance (p=0.002) as 59% of patients who have received instructions had high compliance as opposed to the 0% of high compliance among the patients who did not receive instructions on limb care. The sources of instructions whether medical or non-medical had no significance (p=0.014), to high compliance to limb care.

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Discussion

Knowledge on lymphedema has previously been reported in several studies, the primary focus of these studies were on populations with breast cancer-related, podoconiosis related or filariasis related lymphedema.

Among the study respondents 77% of patients have low knowledge while 23% had high knowledge. It is apparent that a majority of individuals depend on medical staff for education regarding lymphedema and only a minority is self-educated through non-medical sources such as media (40%) or family and friends (29%). In comparison, in a recent study done in United States and worldwide, dedicated websites and media (76.0%), physician/primary health care provider (55.5%) and friends and family (32.1%) were reported as the top three most frequently cited sources of information about lymphedema (7). The percentage of knowledge gained from medical staff and family and friends is almost similar between the two studies but there is a large difference between the percentages of those who access media for knowledge.

A study addressing the perceptions of Breast Cancer Related Lymphoedema, educational content, practices, and support experienced by female breast cancer survivors diagnosed with BCRL indicated that the best way to provide both education and support was through interaction with others (81% and 77%, respectively). However the most common method used by health care providers was through printed information, and thus this study identified a disconnect between what health care providers are doing and what the participants felt was most helpful (8).

It is evident that the defect in self-education and reduced accessibility of non-medical resources may be a cause for the poor knowledge regarding lymphedema within our selected patients. Improving the awareness about lymphedema and the importance of proper limb care in patients with lymphoedema via non-medical sources such as media and patient support groups can contribute to increasing the knowledge among patients.

Having perceived previous knowledge on lymphedema and limb care has a significant impact on high compliance, thus preventing the development of complications of lymphedema.

When assessing compliance to limb care 59% of the patients were compliant as opposed to a corresponding study on lymphedema management and morbidity control done in 2003 in Gampaha District, Sri Lanka where it was revealed that 66% of their population was compliant to the care the affected area (9).

This difference may have been due the difference in the sample sizes. The current study was done on 100 patients and the Gampaha study was done on 66 patients. Furthermore, the compliance in this study was based on multiple factors whereas the Gampaha study had focused only on a few. Moreover, the Gampaha study was conducted on residents of 1.387 km2 area of that district alone while this study did not consider the place of residence but the time taken to travel to the clinics as, if it takes less than 1 hour we could consider that it is a positive factor for good compliance as opposed to taking more than 1 hour to reach clinics.

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In this study the compliance to limb care was assessed by inquiring on, washing with clean, cold water which is practiced by 66% of our patient population, whereas the above mentioned study done in Gampaha revealed that only 30% of their population was compiling to washing the affected area. Furthermore we found that 64% of this study population applies soap when washing and use clean gauze. This factor was not analyzed by the corresponding study in Gampaha but it was included in this study as cleaning with aclean gauze is important instead of harmful material such as coils which results in traumatizing the affected area and introducing infections. Moreover, we assessed that antiseptic agents are used by 51% of our sample population as opposed to 90% in the study population in Gampaha and comfortable slippers were used by 47% of our sample patient population as opposed to a higher percentage of 80% in the Gampaha District study population. This data emphasize that more people in their study are compliant to proper cleaning practices, than the current study population. This may be explained by the fact that individuals in this study population probably lack follow up and home visits done by health care facilitators to assess their limb care.

Limb elevation as a vital step in measuring compliance in controlling lymphedema and in this study, 49% of patients practice limb elevation as opposed to 80% of the corresponding study done in the Gampaha patient population. Inquires were made about the time of day that patients elevate their swollen limbs as it is identified that elevation of limbs early morning is more effective than other times of the day in controlling lymphedema. This study reveals that only 17% of the patients elevate their limbs in the morning and most (38%) do so at night. Issues of convenience and practicality may have caused the low percentage of limb elevation in the morning as most of this study population belongs to the middle age category and are busy during the morning hours.

Considering that the use of multilayer bandages is one of the most recognized methods to reverse lymphedema, this was inquired from our patients attending the clinic. Sixty seven percent use multilayer bandages. However in a recent study conducted in Germany out of the 348 participants a majority (86.4%) was treated with compression and from them, most (83.6%) with compression stockings and only 1.4% with bandages or support stockings (10).

It was also revealed that 64% of this study population is involved in exercises to the affected area while a lesser percentage (32%) was involved in exercises, in the corresponding study in Gampaha. Fifty four percent of this study population was concerned in maintaining an ideal body weight whereas only 30.3% percentage of patients in the study done in Gampaha District were concerned about maintaining their ideal body weight.

The higher percentage of patients involved in exercise and maintaining ideal body weight in this study as opposed to the study done in 2003, maybe due to the increased awareness among the general public on the importance of exercise and maintaining body weight due to the rise in Non-Communicable Diseases, and due to the development of walking tracks and increased facilities for physical exercise spread throughout the suburbs of Sri Lanka. Furthermore there was a

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misconception in the past that strenuous exercise aggravates lymphedema and that idea too may have contributed to the low percentage in the 2003 study.

It is known that trauma to a limb with lymphedema can cause cellulitis and aggravate the condition. When inquired about awareness on avoiding trauma it was revealed that 66% among this study population and a comparatively higher percentage of 90% of patients in the corresponding study in Gampaha had awareness on avoiding trauma. Even though no corresponding studies were done on patient awareness regarding identifying early signs of infection we found in this study that 81% have a good knowledge on identifying infection. 73% considered redness while a lesser percentage of 53 % identified that fever too is an early sign of an infection in the swollen area.

Conclusion

Lymphedema even though very difficult to cure, can be controlled and it is vital to prevent the condition from progressing further as it can lead to irreversible fibro sclerotic changes and associated complications. This study revealed that the level of knowledge about lymphedema and its limb care is low but that the compliance to limb care in patients is high. Socio demographic and patient factors such as comorbidities had no significant association with compliance but receiving instructions about limb care had a significant association with high compliance. As evidenced by this study as well other recent studies, effective self-care implementation requires a considerable degree of education, instruction or demonstration and the role of the educated health worker or trained volunteer cannot be ignored.

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References

1. Kathleen M Rossy NSSDJ. Lymphedema: Practice Essentials, Background, Pathophysiology [Internet]. [cited 2019 Jun 21]. Available from: https://emedicine.medscape.com/article/1087313-overview

2. Lawenda BD, Mondry TE, Johnstone PAS. Lymphedema: A primer on the identification and management of a chronic condition in oncologic treatment. CA Cancer J Clin [Internet]. 2009 Jan 1 [cited 2019 Jun 21];59(1):8–24. Available from: http://doi.wiley.com/10.3322/caac.20001

3. Moffatt CJ, Franks PJDD., Doherty DC, et al. Lymphoedema: an underestimated health problem. QJM [Internet]. 2003 Oct 1 [cited 2019 Jun 21];96(10):731–8. Available from: https://academic.oup.com/qjmed/article-lookup/doi/10.1093/qjmed/hcg126

4. Lee BB, Andrade, M AP, et al. Diagnosis and treatment of primary lymphedema. Consensus document of the International Union of Phlebology (IUP)-2013. Int Angiol [Internet]. 2013 Dec [cited 2019 Jun 21];32(6):541–74. Available from:

http://www.ncbi.nlm.nih.gov/pubmed/24212289

5. Karnasula VM. Management of ulcers in lymphoedematous limbs. Indian J Plast Surg [Internet]. 2012 May [cited 2019 Jun 23];45(2):261–5. Available from: http://www.ncbi.nlm.nih.gov/pubmed/23162225

6. Phillips GSA, Gore S, Ramsden A, Ramsden A, Furniss D. Lymphaticovenular anastomosis in the treatment of secondary lymphoedema of the legs after cancer treatment. J Plast Reconstr Aesthetic Surg [Internet]. 2019 Jul [cited 2019 Jun 23];72(7):1184–92. Available from: https://linkinghub.elsevier.com/retrieve/pii/S1748681519301226

7. Deng J, Fu MR, Armer JM, et al. Self-reported information sources and perceived knowledge in individuals with lymphedema. Lymphology [Internet]. 2013 Dec [cited 2019 Jun 21];46(4):173–83. Available from: http://www.ncbi.nlm.nih.gov/pubmed/25141460

8. Ostby PL, Armer JM, Smith K, Stewart BR. Patient Perceptions of Barriers to Self-Management of Breast Cancer–Related Lymphedema. West J Nurs Res [Internet]. 2018 Dec 30 [cited 2019 Jun 21];40(12):1800–17. Available from: http://journals.sagepub.com/doi/10.1177/0193945917744351

9. Chandrasena T, Premaratna R, de Silva NR. Lymphoedema management knowledge and practices among patients attending filariasis morbidity control clinics in Gampaha District, Sri Lanka. Filaria J [Internet]. 2004 Aug 3 [cited 2019 Jun 21];3(1):6. Available from: http://www.ncbi.nlm.nih.gov/pubmed/15287989

10. Herberger K, Blome C, Sandner A, et al. E-Mail Quality of Care of Patients with Chronic Lymphoedema in Germany. 2013 [cited 2019 Jun 23]; Available from: www.karger.com/drm

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Tables

Table 1. Frequency distribution of compliance and knowledge regarding compliance to limb care.

Table 2. Association between compliance and knowledge regarding limb care, in patients with lymphedema.

Table 3. Association between compliance to limb care and age, gender, education level, occupation, comorbidities, receiving instructions about limb care.

Table 1: Frequency distribution of compliance and knowledge regarding compliance to limb care.

	Frequency	Percentage
Compliance		
High Compliance	59	59%
Low Compliance	41	41%
Total	100	100%
Knowledge		
High Knowledge	23	23%
Low Knowledge	77	77%
Total	100	100%

Table 2: Association between compliance and knowledge regarding limb care, in patients with lymphedema.

	Low Compliance	High Compliance	Total	OR (95% CI)	Significance
Low Knowledge	34 (82.9%)	43 (72.9%)	77%	1.807 (0.668-4.891)	p= 0.24
High Knowledge	7 (17.1%)	16 (27.1%)	23%		
Total	41%	59%	100%		

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Table 3: Association between compliance to limb care and age, gender, education level, occupation, comorbidities, receiving instructions about limb care.

Patient Factor	High Compliance	Low Compliance	Total	OR (95% CI)	Significance
Age					
Below or equal to 50	26 (44.1%)	13 (31.7%)	39%	0.589	p= 0.217
More than 50	33 (55.9%)	28 (68.3%)	61%	(0.256-1.358)	
Gender					
Male	24 (40.7%)	13 (31.7%)	37%	0.677	p= 0.361
Female	35 (59.3%)	28 (68.3%)	63%	(0.293-1.565)	
Education					
Up to O/Ls	47 (79.7%)	32 (78%)	79%	0.908	p= 0. 846
Above O/Ls	12 (20.3%)	9 (22%)	21%	(0.343-2.404)	
Occupation					
Not occupied	21 (35.6%)	16 (39%)	37%	1.158	p= 0.727
Occupied	38 (64.4%)	25 (61%)	63%	(0.508-2.638)	
Marital Status					
Unmarried	17 (28.8%)	7 (17.1%)	24%	0.509	p=0.176
Married	42 (71.2%)	34 (82.9%)	76%	(0.189-1.368)	
Comorbidities					
Yes	22 (37.3%)	14 (34.1%)	36%	0.872	p= 0.751
No	37 (62.7%)	27 (65.9%)	64%	(0.379-2.007)	
Interference due to comorbidities					
Yes	17 (28.8%)	11 (26.8%)	28%	0.906	p= 0.830
No	42 (71.2%)	30 (73.2%)	72%	(0.371-2.209)	
Received Instructions					
No	0 (0%)	6 (14.6%)	6%	2.686	**p= 0.002**
Yes	59 (100%)	35 (85.4%)	94%	(2.066-3.492)	
Sources of instructions					
Medical	50 (84.7%)	26 (63.4%)	76%	3.205	p= 0.014
Non-medical	9 (15.3%)	15 (36.6%)	24%	(1.236-8.309)	