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DOES TREATMENT ALLEVIATE LYMPHEDEMA SYMPTOMS? A CROSS-SECTIONAL STUDY EVALUATING PATIENT PERSPECTIVES

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ABSTRACT

Most studies evaluating lymphedema treatment effect focus on objective reductions in limb volume, with little attention given to subjective treatment outcomes. The objective of this work was to describe the range of lymphedema symptoms experienced by patients and the importance of symptom improvement following treatment. The second aim was to explore lymphedema treatment use and the effect of individual treatments on symptoms, from the patient's perspective. Australian adults with lymphedema (n=421) completed a self-administered questionnaire. Information was collected about patients' symptoms, the importance of symptom improvement following treatment, as well as treatment types used and perceived effectiveness of each treatment. In addition to swelling, the vast majority of participants experienced heaviness and tightness in the affected region. Overall, symptoms of lymphedema varied between individuals but the majority considered subjective symptom improvement to be an important outcome of treatment. The most commonly used treatments were compression garments, self-massage, prescribed exercises, and manual lymph drainage, and the majority (95%) of participants had used multiple treatments to manage their lymphedema. The impact of treatments on subjective symptoms varies widely between treatments. Consequently, in addition to objective measures of swelling, it is important to include patient-reported outcomes in future prospective lymphedema treatment studies.

Keywords: lymphedema, treatment, symptoms, patient-reported outcomes, compression, massage

Lymphedema is characterized by impaired drainage of lymphatic fluid, resulting in swelling and a range of other physical symptoms, including heaviness, tightness, pain and numbness (1,2). Primary lymphedema develops due to an inherited or developmental abnormality in the lymphatic system, while secondary lymphedema is caused by trauma or injury (2). Worldwide, the most common cause of secondary lymphedema is the parasitic infection filariasis, while in developed countries the primary cause of secondary lymphedema is cancer treatment (3). It is among the most feared complications following cancer treatment (4) and in many cases has significant physical, psychological, and social implications (5-7). Individual experiences of lymphedema vary, with some experiencing acute onset and relief of symptoms and others developing a chronic condition (8,9). While some people are prone to exacerbations resulting in severe swelling and skin infections, others have relatively stable symptoms.

Regardless of the etiology, the methods used to treat the condition are the same.

Conservative treatments are initially prescribed, with surgical options considered when patients no longer respond to conservative options (10). Although high quality evidence to support lymphedema treatment guidelines is limited (3,11,12), treatments including complex physical therapy (CPT), manual lymph drainage (MLD), compression (bandages, garments and pneumatic compression pumps), low-level laser, and exercise, are the most widely prescribed forms for lymphedema (13,14). Complex physical therapy (also called complex decongestive therapy) consists of two phases, a treatment phase followed by a maintenance phase, and combines four lymphedema treatment strategies: manual lymph drainage, compression, skin care, and limb exercises (15). Many of these treatments require considerable commitment from patients, in terms of the financial costs, time and effort involved. In addition, many people with lymphedema require assistance from another person to perform self-management components of their treatment.

Long term treatment success is likely to be influenced by adherence to treatment (16), but little attention has been given to patients' experiences of treatment. Most studies of treatment effect focus on objective reductions in limb volume only. While these are important outcome measures in intervention studies, less attention has been paid to other symptoms of lymphedema, and whether treatments have any effects on these. This represents an important gap in the literature since previous studies have reported no associations between limb volume and quality of life, but quality of life detriments are evident in highly symptomatic patients (17-21). This study aimed to determine the range of symptoms experienced by people with lymphedema and the importance of symptom improvement as a treatment outcome. An additional aim was to describe patients' treatment use and perspectives of treatment effect for alleviating the range of lymphedema symptoms experienced.

METHODS

This cross-sectional study recruited a convenience sample of people with lymphedema. Following ethical approval by the Queensland University of Technology Human Research Ethics Committee, participants were approached for the study through the Lymphedema Association of Queensland (LAQ), the Lymphedema Association of Victoria, and an International Society of Lymphology patient information session in Sydney, Australia. Self-administered questionnaires were sent to 1,030 members of the associations. Approximately 43% (n=441) completed and returned the questionnaire. Twenty participants were excluded as they did not meet the eligibility criteria of being 18 years or over, with diagnosed lymphedema. Consequently, data from 421 participants was included in the final analysis.

Self-Administered Questionnaire

Patients indicated whether or not they had experienced ten possible lymphedema symptoms, including swelling, heaviness, tightness, aching, tenderness, stiffness, weakness, numbness, pain, and range of movement deficit. The symptoms included were determined by those most often identified in the literature (22) and through consultation with people with lymphedema, an experienced lymphedema physiotherapist, and a researcher familiar with lymphedema. Participants were asked whether they considered improvements in each physical symptom an important outcome of treatment using a Likert-scale with 5 categories ranging from not important at all to very important.

To determine the extent of mainstream treatment use, participants were asked to indicate which treatments they had ever used to treat their lymphedema. Mainstream treatments were determined by those regularly prescribed by health professionals in a study conducted by Langbecker et al (13) and included CPT, MLD, compression garments,

bandages and pumps, prescribed exercises, self-massage, and laser therapy. Surgery was also included as it has become more commonly used in recent years. Perceived effectiveness of each form of treatment was measured for all 10 lymphedema symptoms by asking participants to indicate whether for each of the treatments they had used, it helped each symptom "very little/little," "somewhat/moderately," or "quite a lot/very much". In addition, participants were invited to provide any additional information about their symptom or treatment experience in an open-ended question.

The questionnaire also collected information on demographic characteristics including age, gender, marital and parental status, living arrangements, and socio-economic status (as defined by education level, employment status, private health insurance, and income). Information relating to lymphedema location, duration and characterization (single episode, recurrent, or persistent) was assessed separately for each limb segment, as well as the groin and trunk.

Statistical Analysis

Descriptive statistics (means, standard deviations, and proportions) were used to describe personal and lymphedema characteristics of the sample. Frequencies of symptoms and mainstream treatment options were computed to determine their prevalence. Counts and proportions were used to describe the importance of improvement in symptoms and other lymphedema-associated outcomes, as well as perceived effectiveness for 10 different symptoms. All available data were used, resulting in different numbers of participants across treatments and symptoms. The relevant numbers of participants contributing to each outcome are provided in all tables. Data analyses were performed using SPSS version 18.

RESULTS

Participant Characteristics

The majority of participants were 55 years or older, with a median age of 66.0 years (min=18.0, max=91.0), and most (95%) were female. Approximately half of the participants lived with partners, friends, or relatives (52%), and around 10% had children living at home. Just over 40% had education levels of Year 12 completion or less, and 44% had annual household incomes below $52,000. More than three quarters of participants had private health insurance (77%). The majority of participants had secondary lymphedema (78%) and of these, most had developed lymphedema following cancer treatment (83%). Among those who had developed lymphedema following cancer, 70% had been diagnosed with breast cancer, 16% had gynecological cancer and 14% had other cancer types. Similar proportions of participants had upper limb lymphedema (ULL, 46%) and lower limb lymphedema (LLL, 43%) and 11% had symptoms affecting multiple areas of the body. The majority of participants had lymphedema for more than 3 months (84%), and described their lymphedema as 'persistent' (78%).

Lymphedema Symptoms

In addition to swelling (reported by 99% of participants), the vast majority of participants (89%) experienced heaviness and/or tightness as a symptom of lymphedema (*Table 1*). Over 75% experienced aching and/or indicated they had reduced range of movement in the affected limb. More than half of all participants had experienced each individual symptom.

Importance of Improvement in Symptoms Following Treatment

Of the 10 lymphedema symptoms queried, more than 60% of those with swelling, heaviness, tightness, and reduced range of movement reported improvements in those

TABLE 1
Patient Reported Importance of Improvement in Symptoms Following Treatment

Symptom	Had symptom n (%)	Very important n (%)	Important n (%)	Not important[a] n (%)
Swelling	418 (99.3)	301 (72.0)	83 (19.9)	37 (8.1)
Heaviness	375 (89.1)	236 (62.9)	93 (24.8)	92 (12.3)
Tightness	375 (89.1)	225 (60.0)	97 (25.9)	99 (14.1)
Reduced range of movement	328 (77.9)	209 (63.7)	68 (20.7)	144 (15.5)
Aching	323 (76.7)	183 (56.7)	88 (27.2)	150 (16.1)
Tenderness	286 (67.9)	140 (49.0)	76 (26.6)	205 (24.5)
Pain	275 (65.3)	157 (57.1)	68 (24.7)	196 (18.2)
Stiffness	261 (62.0)	134 (51.3)	71 (27.2)	216 (21.5)
Weakness	254 (60.3)	112 (44.1)	67 (26.4)	242 (29.5)
Numbness	225 (53.4)	101 (44.9)	56 (24.9)	264 (30.2)

[a]not important includes those who responded 'does not bother me,' 'not applicable,' or missing.

symptoms following treatment as being very important. No less than 40% of participants who noted individual symptoms said improvements in that symptom were very important outcomes of treatment.

Treatment Use

At least two-thirds of participants had used compression garments (86%), self-massage (79%), prescribed exercises (69%), or MLD (67%) to treat their lymphedema (*Table 2*). In addition, compression bandaging and/or CPT were used by 45% and 42% of participants, respectively. Between 3 and 18% had used laser therapy, pneumatic compression pumps (PCP), and/or had surgery to treat their lymphedema (18%, 12%, 3%, respectively). Over half (62%) of all participants had used more than four lymphedema treatment types, while 5% had used only one type of lymphedema treatment.

TABLE 2
Use of Mainstream Treatment Options by People with Lymphedema (n=421)

Treatment	n	(%)
Compression garment	362	(86.0)
Self-massage	332	(78.9)
Prescribed exercises	291	(69.1)
Manual Lymph Drainage	285	(67.3)
Compression bandaging	188	(44.7)
Complex Physical Therapy	176	(41.8)
Laser Therapy	77	(18.3)
Pneumatic Pumps	51	(12.1)
Surgery	14	(3.3)

Perceived Effectiveness of Lymphedema Treatment Types

Regardless of the treatment used, at least one in five, and up to 60% of participants (who experienced a particular symptom) perceived their lymphedema treatment (regardless of treatment type) as effective in treating their swelling (26 to 60% across treatment types), heaviness (23 to 50%), tightness (23 to 52%), and aching (20 to 40%)

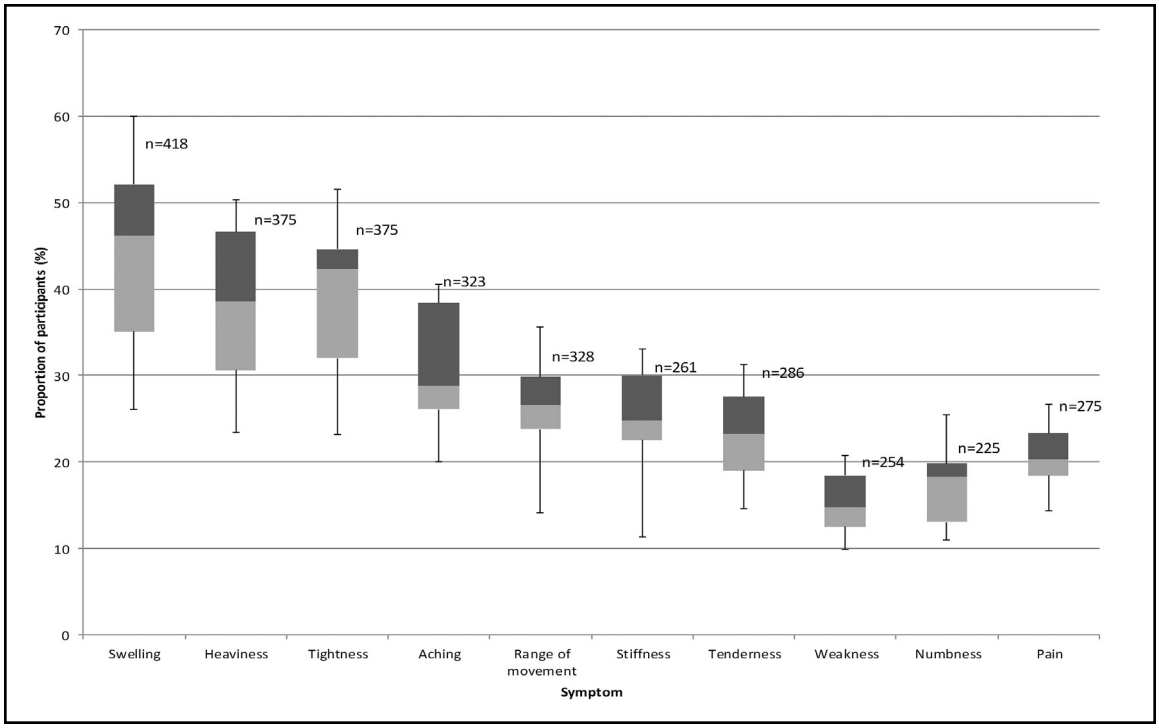

Fig. 1. Box plot of the proportions of participants who reported improvements in symptoms following any type of lymphedema treatment. Boxes represent median (and interquartile ranges) proportions across nine different treatment types.

(*Fig. 1*). Lower proportions of participants reported improvements in weakness, numbness, and pain (median proportions <20%) following any type of treatment.

Responses to the open-ended question about lymphedema and associated treatment highlighted that, in some cases, success of treatment was due to a combination of strategies being used. The quotes below provide additional insight;

"After original diagnosis and treatment, the pain, movement and general well being improved greatly. Compression garment worn every day for years. Exercises and hydrotherapy kept me mobile and virtually pain free."

"I am currently using a range of treatments. Between them, they seem to give me some overall relief and help to prevent my lymphedema from becoming worse. No one treatment on its own would achieve this."

Proportions of patients who experienced each symptom and who found their treatment effective for improving their symptoms are presented in *Table 3*. Across all symptoms, CPT, compression garments, compression bandaging and MLD were perceived as effective at improving a range of lymphedema symptoms by the highest proportions of participants. For each symptom, 18 to 60% of participants reporting improvements following each of these treatments (shaded in *Table 3*). By comparison, self-administered massage and prescribed exercises consistently had the lowest proportions of participants reporting the treatments as effective at improving symptoms.

When considering individual symptoms, some specific treatments resulted in greater or lesser effects on specific symptoms (*Table 3*). For example, almost half of all participants who had used laser therapy (47%) reported

TABLE 3
Proportions of Participants Who Reported Improvement in Lymphedema Symptoms Following Use of Various Conservative Treatments

Swelling n(%)[a]	Heaviness n(%)[a]	Tightness n(%)[a]	Aching n(%)[a]	Tenderness n(%)[a]	Stiffness n(%)[a]	Weakness n(%)[a]	Numbness n(%)[a]	Pain n(%)[a]	ROM n(%)[a]
CG	CPT	CPT	CPT	CPT	CPT	CPT	CPT	CG	CPT
216	83 (50.3)	86 (51.5)	60 (40.5)	41 (31.3)	41 (33.1)	25 (20.7)	27 (25.5)	63 (26.7)	53 (35.6)
CPT	CB	LAS	CG	CG	PCP	CG	MLD	MLD	SURG
105	79 (46.7)	34 (46.6)	108	74 (29.7)	11 (32.4)	44 (19.7)	35 (21.6)	53 (26.4)	4 (30.0)
CB	CG	CB	MLD	MLD	SURG	CB	CB	CPT	PCP
98	153 (46.6)	78 (44.6)	88 (38.4)	57 (27.5)	3 (30.0)	23 (18.4)	21 (19.8)	30 (23.3)	14 (29.8)
SURG	MLD	CG	CB	CB	MLD	MLD	CG	CB	CB
7 (50.0)	109 (41.6)	138 (42.9)	51 (32.1)	32 (23.2)	53 (27.6)	34 (18.0)	36 (18.7)	30 (22.9)	44 (27.3)
MLD	SURG	MLD	LAS	LAS	CB	PCP	PCP	LAS	MLD
132	5 (38.5)	112 (42.3)	19 (28.8)	13 (23.2)	31 (24.8)	5 (14.7)	6 (18.2)	12 (20.3)	61 (26.6)
PCP	LAS	SURG	SURG	SURG	LAS	PE	SURG	SURG	PE
22	22 (30.6)	5 (35.7)	3 (27.3)	2 (20.0)	13 (23.6)	26 (14.0)	1 (14.3)	2 (20.0)	58 (24.6)
LAS	PCP	PCP	PCP	PCP	CG	SURG	LAS	PCP	CG
27	15 (30.6)	16 (32.0)	12 (26.1)	8 (19.0)	51 (22.5)	1 (12.5)	6 (13.0)	7 (18.4)	69 (23.8)
PE	PE	PE	PE	PE	PE	SAM	SAM	PE	LAS
78	64 (24.3)	65 (24.3)	50 (21.9)	30 (15.1)	43 (22.5)	22 (10.2)	24 (12.6)	33 (16.6)	14 (21.2)
SAM	SAM	SAM	SAM	SAM	SAM	LAS	PE	SAM	SAM
86	71 (23.4)	71 (23.2)	53 (20.0)	34 (14.6)	25 (11.3)	5 (9.8)	18 (11.0)	33 (14.3)	38 (14.1)

Shading highlights the four treatments for which the highest proportions of participants reported improvements in symptoms; [a]Proportions of patients who used the treatment and had the symptom: ROM – Range of movement; CG – Compression garments; CPT – Complex physical therapy; CB – Compression bandaging; SURG – Surgery; MLD – Manual lymph drainage; PCP – Pneumatic compression pumps; LAS – Laser therapy; PE – Prescribed exercises; SAM – Self-administered massage

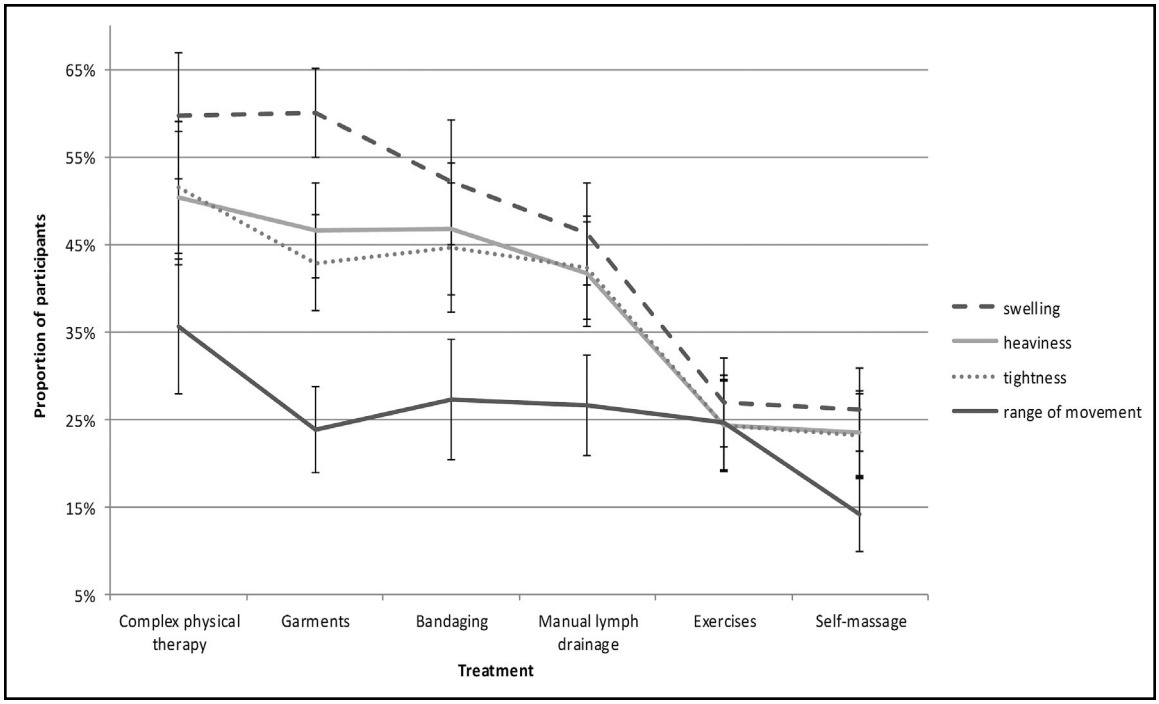

Fig. 2. Proportions of participants with each symptom who reported improvements in swelling, heaviness, tightness, and range of movement following use of different types of treatment.

improvements in tightness. Subjective improvements in swelling, the most common symptom of lymphedema, were reported by at least one in two participants who used compression garments, CPT, compression bandaging, and/or surgery to treat their lymphedema (60%, 60%, 52%, and 50%, respectively).

Improvements in swelling, heaviness, tightness, and range of movement were considered very important treatment outcomes by at least 60% of participants. Improvements in these symptoms following treatment are presented in *Fig. 2*, and were reported by the highest proportion of participants following the use of CPT. While 40-60% of participants who used compression garments also reported improvements in swelling, heaviness, and tightness, improvements in range of movement were reported by less than 25% of those who used garments (*Fig. 2*).

Responses to the open-ended question confirmed participants felt compression garments, in particular, were an important part of maintaining symptom improvements in the longer term, as described below.

"I have learnt to live with the fact that I cannot go without wearing my compression garments."

"I was diagnosed very soon after my operation and received treatment straight away. Early on I did recommended exercises daily also, but found the garments kept the condition under control."

DISCUSSION

A range of treatments are commonly prescribed for patients with lymphedema, with varying scientific evidence to support their use (3,11,2,23,24). Studies investigating treatment effect typically measure limb size before and after a program of treatment.

However, findings from previous studies have found that quality of life is not associated with limb size (17,20,21,25,26). Therefore, it is plausible other symptoms of lymphedema have greater impact on quality of life and reported improvements following treatment (18,20,27,28) are due to improvements in lymphedema symptoms other than measurable changes in swelling.

This study confirmed that patients' experiences of lymphedema, associated symptoms and effect of treatments to alleviate these symptoms vary widely. Almost all participants reported swelling at the time of completing the study, and 89% also experienced heaviness and/or tightness of the affected area. Interestingly, while pain is not typically considered a common symptom of lymphedema and is rarely documented in studies of lymphedema treatment (27), 65% of participants in the current study reported experiencing pain. The vast majority of people with lymphedema felt symptom improvement, beyond objective reductions in swelling, were important outcomes of treatment. Improvements in swelling, heaviness, tightness, and range of movement were reported as 'very important' or 'important' treatment outcomes by nine of 10 participants. Of those who experienced pain, over 80% felt reduced pain following treatment was a 'very important' or 'important' treatment outcome. These findings add to those from previous studies that have suggested increased function, softening of tissues, reduced shape distortion, and reducing likelihood of infection may be as equally important to patients as reductions in limb volume (29, 30).

People with lymphedema use a range of treatments to manage their symptoms. In the current study, treatments reported by higher proportions of participants, including compression garments, self-massage, exercises, and MLD, were in line with the most commonly prescribed treatments by health professionals, reported by Langbecker et al (13). However, fewer participants in the current study reported using compression bandaging (45%) when compared with the proportion of health professionals who prescribed compression bandaging (72%) for their patients with lymphedema (13). While treatment use in this study was similar to findings from an Australian study of women with breast cancer-related lymphedema (31), there were some noteworthy differences when compared with findings from a population-based study in the UK. For example, MLD was used by 67% and 4%, and self-massage by 79% and 17% of study participants, respectively. This could be due to differences in participants recruited by purposeful sampling versus population-based sampling, or may indicate different prescribing practices in Australia compared with the UK. Understanding the differences in treatment use is important as it may suggest location- or population-specific barriers to treatment requiring particular attention.

Findings from randomized, controlled trials support the use of compression therapy to treat lymphedema. These trials reported reductions in limb volume and/or circumferences following use of compression garments and bandages alone with greater reductions reported when compression was combined with other physical therapies (11,12,14). Results from the current study confirmed compression garments and bandages were also perceived by people with lymphedema to improve a range of other lymphedema symptoms, including heaviness and tightness. The scientific evidence to support other treatment modalities is limited but findings from this study suggest only some patients experience improvements in lymphedema following their use. Improvements in individual symptoms were measured in this study as it was considered possible that a treatment which improved pain or numbness without having a significant impact on limb volume could still be considered as valuable and important as a treatment which has proven effective in reducing limb size. Although the effects of pneumatic compression pumps, MLD, laser therapy, and prescribed

exercises have been inconsistent when considering limb size as the primary treatment outcome (12,32,33), many participants in this study reported positive effects of these treatments on a range of symptoms. For example, compression pumps were reported as effective for improving stiffness and range of movement by higher proportions than other types of compression. Similarly, MLD and laser therapy were reported as improving tightness by over 40% of participants who used these treatments and experienced tightness. In addition, around one in four participants who used exercises reported improvements in swelling, heaviness, tightness, and range of movement. These findings provide important information for health professionals treating patients who may want assistance with managing specific symptoms.

A difficulty with investigating treatment outcomes for lymphedema is that patients often use multiple treatments concurrently, making it impossible to determine the individual contribution of treatments for symptom relief. However, the quantitative and qualitative data collected from this study suggest that people use multiple treatments to improve different symptoms and that overall, better subjective outcomes are achieved when treatments are combined. Incorporating patient-reported outcomes into descriptive or intervention studies where treatment protocols are carefully defined, controlled, or monitored could help to identify direct effects of different treatments on symptoms.

While this study included people with primary and secondary lymphedema, men were under-represented and the convenience sampling approach may limit the representativeness of the sample to the wider lymphedema population. As members of support organizations, participants may have experienced more symptoms and sought access to a wider range of treatments than those with lymphedema in the general population. The study design was cross-sectional, with participants needing to recall perceptions about treatments they may not have been currently using, potentially introducing recall bias. Nonetheless, this study is the first to explore the effect of available lymphedema treatments on 10 individual symptoms from the patient's perspective and provides valuable information to be incorporated in future longitudinal studies of treatment effect and adherence.

The symptoms of lymphedema can have a significant impact on physical function and mobility, as well as social and psychological implications. Findings from this study suggest treatments found to reduce limb volume in previous studies, including CPT and compression therapy, are also effective for improving a range of other physical symptoms. In addition, a number of treatments that currently lack a scientific evidence base were reported to improve participants' objective symptoms. For people with multiple, chronic symptoms of lymphedema, there is no single treatment currently regarded as a 'gold standard' and combining treatments may be necessary to manage symptoms effectively. Findings from this study highlight the need to consider patient-reported measures in addition to measures of limb volume in future intervention research. It is important for researchers, health care services and health professionals to consider individual circumstances and responses to treatment to maximize long-term adherence and optimize treatment outcomes.

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