

Lymphoedema therapist practice, then and now: 2009–2018 international survey results

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Key words

Lymphoedema, practice, survey, therapist

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Abstract

The American Lymphedema Framework Project (ALFP) collected online survey data from trained lymphoedema therapists in 2009 (nationally) and 2018 (internationally) to document characteristics of therapists' practice, population served, settings and educational preparation. Comparative analysis of data between survey years was completed to explore changes in the field. Therapists' mean age increased significantly, as did years of practice. Physical and occupational therapy continued to be the dominant educational preparation for therapists, with the number of massage therapists increasing over the years. The percentage completing the standard of 135 hours in lymphoedema educational training increased, as did the percentage of therapists specialising in lymphoedema care. Therapists self-reported an increase in private practice. This comparison highlights both developments and practice gaps in the field, helping stakeholders and therapists worldwide address growing needs in lymphoedema care.

A total of 19.3 million people were diagnosed with cancer worldwide in 2020. This number is expected to increase to 28.4 million cases in 2040 (Sung et al, 2021). Cancer survival statistics vary between countries and depend on: 1) cancer type; 2) treatment available; 3) stage at diagnosis; and 4) start of treatment (World Cancer Research Fund International, n. d.). Currently, there are nearly 17 million cancer survivors in the USA (American Cancer Society, 2022). The last several decades have seen an increase in the number of people living with cancer worldwide as treatments and symptom management practices extend survivorship and improve quality of life (Sung et al, 2021). While improved and innovative cancer treatments have increased the survivorship population,

survivors often must learn to live with the side effects of these treatments over their lifetime.

One cancer treatment side effect is lymphoedema (LE). LE is a condition associated with interruption of intact lymphatic function and corresponding movement of protein-rich fluid from the interstitial spaces, causing debilitating limb and truncal swelling (Armer et al, 2020; International Society of Lymphology, 2020). Primary lymphoedema results from a genetically-influenced abnormal development in a part of the lymphatic transport system. Secondary lymphoedema develops from a trauma to the lymphatic system caused by injury (e. g., burns or trauma), cancer treatment, infection or decreased venous capacity.

Worldwide, secondary lymphoedema

is predominantly caused by the parasitic infection of filariasis (International Society of Lymphology, 2020). Another common cause is cancer treatment, resulting from the traumatic effects of surgery, chemotherapy, and radiation treatments on lymphatic function (Armer et al, 2020). Breast cancer treatment has been recognised as the primary cause of secondary lymphoedema in the USA and other developed countries for many years (McLaughlin et al, 2020). Literature has increasingly documented other cancer treatments which impact the lymphatic system and may lead to lymphoedema development, including head and neck (Tyker et al, 2019), colorectal, gynecological and prostate cancers (Chaput et al, 2020; Ding et al, 2020; Hutchison, 2018). In addition, there is growing evidence that oedema associated

with chronic venous insufficiency may be a result of lymphatic dysfunction (Dean et al, 2020; Moffatt et al, 2019).

There is as yet no cure for lymphoedema, but volume reduction and symptom management can control the impact on physical function, support psychosocial wellbeing, and optimise quality of life. The 'gold standard' management for lymphoedema is complete decongestive therapy (CDT), involving manual lymphatic drainage (MLD), compression bandaging/garments, skin care, exercise, and injury avoidance, guided by certified lymphoedema therapists (International Society of Lymphology, 2020). The work of the lymphoedema therapist is critical to minimising the impact of lymphoedema on survivor quality of life. It is important to understand therapists' perceptions of practice environment, the requirements for certification, and the challenges they face in caring for survivors living with this condition.

The American Lymphoedema Framework Project (ALFP) was established in 2008 as a collaboration of stakeholders in the lymphoedema space, including researchers, healthcare professionals, advocates, patients, family members, industry partners and policy-makers (Armer et al, 2010). Led by clinical and research experts in lymphoedema care, the ALFP works to evaluate the care provided to people living with lymphoedema and promote expert care both in the USA and worldwide.

A survey of therapists' practice was conducted in 2009 by the ALFP to provide a picture of the US therapist role (Armer et al, 2010). With the increase in cancer survivors, it is important to discover if changes have occurred in the practice context of this vital cancer survivorship team member both in the USA and internationally. In 2018, the new survey link was made available to US and international therapists through organisational posts, email invitations and snow-balling to collect information on current practice. The 2018 study results have been published elsewhere (Anderson et al, 2019). Additional descriptive-comparative analysis was performed to examine the differences between the 2009 and 2018 results, in order to explore practice changes evolving over these nine years and describe the lymphoedema therapist of today.

Methods

The 2009 ALFP survey was updated based on an online search of current lymphoedema therapist practice settings and certification

requirements (Anderson et al, 2019). Survey questions were reviewed by the research team members and concerns were discussed until consensus was achieved. Fifty-six questions were imported into the Qualtrics™ (Qualtrics, Provo: UT) survey system. The ALFP stakeholder database provided the initial participant pool, with snowball sampling expanding the survey reach from October to December 2018. Survey question topics and participant recruitment details have been reported elsewhere (Anderson et al, 2019). The University of Missouri Institutional Review Board approved this study project (MUIRB 1138778).

Results

A total of 415 therapists from 46 states within the US completed the 2009 online SurveyMonkey survey. A total of 950 therapists completed the 2018 online Qualtrics survey. The majority of 2018 respondents were from the USA (73%, $n=662$), representing 46 states among those reporting a state. All seven Canadian provinces and 41 other countries participated ($n=288$). Therapists from the following countries responded: Japan, Ireland, New Zealand, Slovenia, Taiwan, Turkey, Afghanistan, Philippines, Italy, Singapore, People's Republic of China, Moldova, Gibraltar, Cyprus, Greece, Jordan, Qatar, Cayman Islands, Zimbabwe, Puerto Rico, India, Venezuela, South Africa, Netherlands, Malaysia, Austria, Bulgaria, South Korea, Poland, Spain, Angola, Brunei, United Arab Emirates, Finland, Albania, Kenya, Mexico, Hong Kong and Iraq.

Frequencies, means and standard deviations were calculated for participant demographics for the 2009 and 2018 survey data. An independent t-test was utilised to compare the averages of therapist age and practice years between the 2009 and 2018 data. On average, the age of a therapist in 2018 was 49.79 years ($n=654$, $SD \pm 11.18$), higher than in 2009 when it was 45.17 ($n=403$, $SD \pm 9.60$), with a significant difference in the mean ages of 4.62 years ($t(950) = -7.15$, $P < .001$, 95% CI [-5.87, -3.35]). On average, the reported mean number of practice years of a therapist in 2018 was 10.62 ± 7.6 ($n=667$), an increase from 2009 ($n=384$, $M = 7.15 \pm 4.70$ years), with a significant difference in the mean practice years of 3.47 years ($t(1045) = -9.18$, $P < .001$, 95% CI [-4.22, -2.73]). In both 2009 and 2018, more females than males reported providing lymphoedema therapy (95% vs. 5%; 94% vs. 6%; *Table 1*).

Physical and occupational therapy continued to be the primary professional educational preparations for lymphoedema therapists. The percentage of respondents reporting educational background who identified as massage therapists alone or massage therapists with other professional backgrounds almost doubled from 13% to 23.82% from 2009 to 2018. Physical and occupational therapy assistants, along with athletic trainers, registered nurses, advanced practice nurses, and physicians, continued to provide lymphoedema therapy (*Table 1*).

Frequencies were calculated for each question and Z-test was used to determine if the differences between responses concerning: 1) initial certification; 2) advanced training; 3) LE specialisation; and 4) Lymphology Association of North America (LANA)-certification rates between the 2009 survey and 2018 survey were significant. Compared to 2009, the majority of participating therapists in 2018 (95.60% [$n=646$] vs. 93% [$n=374$]) completed a 135-hour therapist course (1/3 didactic, 2/3 skill practice), which was the professional standard for certification. The number of lymphoedema therapists with advanced training beyond their initial certification course decreased by over 20 percent since 2009 (60.4% [$n=238$] vs 44.2% [$n=299$]). Therapists specialising in areas of lymphoedema therapy increased by 12% (26.9% [$n=180$] to 14.2% [$n=55$]); $z = -0.13$, $P = .90$). Lymphoedema therapists in North America who completed the LANA certification decreased by 9 percent since 2009 (41.2% [$n=164$] to 32.1% [$n=217$]; $z = 3.50$, $P = .00046$).

The reported location of therapy practice settings changed between 2009 and 2018. Hospital-based outpatient clinic settings for treating lymphoedema decreased by 20 percent (64.6% [$n=268$] to 46.8% [$n=406$]; $z = 6.16$, $P < .00001$). Inpatient clinic settings remained constant (13%). Private practice has increased 10% since 2009 (25.8% [$n=107$] to 37.8% [$n=327$]; $z = 1.503$, $P = 1.34$). LE therapists practicing home care and hospice services increased slightly, from 7.5% [$n=31$] to 9.5% [$n=82$]. Comprehensive and community cancer centers and multi-or single-clinic sites continued to represent less than 8% of the practice settings for LE therapists.

In 2018, over 87% of therapists reported offering CDT as a treatment modality compared to 97.3% in 2009, supporting current best practice recommendations for effective lymphoedema management (Armer et al,

Table 1. Lymphoedema therapist comparison.		
Variables	2009 results*	2018 results
Sample	n=415 Female: 95% Male: 5%	n=950 Female: 94% Male: 6%
Therapist background	Educational prep: PT: 49.5% OT: 33.8% Massage therapy: 12.9% Other: PT assistant (5.7%), nurse (2.2%), OT assistant (1.5%), medical doctor (0.5%), athletic trainer (0.5%) Average practice time: 7.15 years (SD ± 4.75) (n=384)	Educational prep: PT: 45% OT: 31.32% Massage therapy: 23.82% Other: PT assistant (3.82%), OT assistant (2.21%), athletic trainer (2.06%) exercise physiology (1.47%), advanced practice nurse (0.88%), medical doctor (0.29%), Other (10.44%) Average practice time: 10.71 years (SD ± 7.71) (n=667)
Therapist training characteristics	93% [n=374] completed 135+ hours of training (1/3 didactic, 2/3 hands-on tuition) 60.4% (n=238) had advanced training beyond 135 hours 14.2% (n=55) specialisation in LE therapy 41.2% (n=164) LANA-certified	95.6% [n=646] completed 135+ hours of training (1/3 didactic, 2/3 hands-on tuition) 44.2% (n=299) had advanced training beyond 135 hours 26.9% (n=180) specialisation in LE therapy 32.1% (n=217) LANA-certified
Therapist practice settings	Hospital-based outpatient: 64.6% (n=268) Private practice: 25.8% (n=107) Hospital-based inpatient: 13.5% Home care/hospice: 7.5% (n=31) Comprehensive cancer centre: 7.2% Multi-clinic: 3.4% Single clinic: 4.6% Community cancer centre: 1.2% Other: 7.7%	Hospital-based outpatient: 46.88% (n=406) Private practice: 37.8% (n=327) Hospital-based inpatient: 12.70% Home care/hospice: 9.47% (n=82) Comprehensive cancer centre: 6.70% Multi-clinic: 6.12% Single clinic: 6.00% Community cancer centre: 1.85% Other: 9.58%
Treatment modalities	Most common treatment: CDT (97.3% [n=404]) Less than 15%: single-phase pneumatic compression devices, vibrator treatment, low-level laser, reflexology Reported treating secondary LE: 83.59% Reported treating primary LE: 16.41% Areas of oncology-related LE: UE: 50.89% LE: 26.32% Trunk: 14% H&N: 5.18% Genitals: 3.6% Treatment required: Wound care: 3.52% LE care: 82.35% Both required: 14.12%	Most common treatment: CDT (87% [n=855]) Less than 15%: single-phase pneumatic compression devices, low-level laser treatment, and aquatic therapy. Reflexology (23%) and Vibrator treatment (47%) increased Reported treating secondary LE: 83.51% Reported treating primary LE: 16.48% Areas of oncology-related LE: UE: 52.65% LE: 30.57% Trunk: 6.95% H&N: 7.66% Genitals: 2.14% Treatment required: Wound care: 2.54% LE Care: 80.80% Both required: 16.65%
<p>Notes: 2009 results were published: Armer et al (2010). Areas of oncology-related LE reflects a portion of 100%, as each respondent provided a percentage of the total.</p>		

2020; International Society of Lymphology, 2020). Secondary lymphoedema continued to be the predominant lymphoedema treated by therapists (*Table 1*). The primary site of oncology-related lymphoedema remains the upper extremity (50.89% vs 53%; $z = 3.812, P = .00014$), with a decrease in treating truncal and genital lymphoedema reported (7%, respectively). Therapists self-reported lymphoedema care continued to be the primary treatment required in their caseload, with a 2% decrease in wound care alone and a corresponding increase in patients requiring both lymphoedema and wound treatment.

Discussion

The lymphoedema therapist is a critical member of the healthcare team. Their expert skill in assessing, treating, and educating people living with lymphoedema supports the life-long management of this condition to improve physical function, psychosocial resilience, and overall quality of life (Sayegh et al, 2017; International Society of Lymphology, 2020). The trained lymphoedema therapist plays an important role in the multidisciplinary collaboration needed for successful management of lymphoedema (Ostby et al, 2014; Chaput et al, 2020; Lentz et al, 2021).

Surveying the characteristics of current lymphoedema therapists and the care environment in which they practice and examining these characteristics over time is important. Through this analysis, we can better understand how the care environment has changed. We can also identify potential challenges and identify practice gaps in providing effective care. The comparison results showed the average reported practice years significantly increased between 2009 and 2018 (*Table 1*). This growth in experience can provide critical support to the growing number of people living with lymphoedema. Confidence associated with this increase in years of practice can strengthen the ability of lymphoedema therapists to collaborate with the healthcare team in active surveillance activities and self-management maintenance (Hutchison, 2018; Ding et al, 2020; Koelmeyer et al, 2021). Davies et al (2020) created clinical practice guidelines for people living with breast cancer-related lymphoedema and pointed out the need for further research to determine the relationship between therapist training and expertise and treatment outcomes. In addition, the lymphoedema care community should carefully monitor this workforce dynamic to sustain this continued

growth and skill development of this critical lymphoedema care resource.

Physical and occupational therapists continue to be the primary providers of lymphoedema therapy (*Table 1*). From 2009 to 2018, the percentage of lymphoedema therapists self-reporting being physical and occupational therapists decreased (49.5% [$n=199$] to 45% [$n=306$]; 33.8% [$n=136$] to 31.32% [$n=213$], respectively). The significant increase in the number of massage therapists providing lymphoedema therapy added much needed numbers of therapists to address the growth of worldwide care requirements. In addition, in 2018, other therapy backgrounds were self-reported, including exercise physiologists and advance practice nurses. The therapist background varied among countries depending on the composition of the healthcare team. This variation may have contributed to the change in practice numbers between the surveys.

The survey comparison illustrated changes in therapist training characteristics since 2009. The number of therapists completing a 135-hour programme increased (93% [$n=374$] to 95.6% [$n=646$]), but fewer progressed to advanced training beyond this initial programme. In addition, for North American therapists, the decrease in LANA-certified therapists may indicate a change in valuing of national certification. This may be a response to lack of increased salary and workplace recognition for the effort demonstrated to obtain this advanced certification or employer reimbursement for related expenses in a time of fiscal constraints. Continued education is important to maintaining awareness of advances in lymphoedema care science and practice to optimise patient outcomes (Deng et al, 2019). Maintaining and retaining highly-skilled therapists to care for the lymphoedema community requires support for lifelong education in the workplace.

The reported practice setting saw a significant change between 2009 and 2018. Private practice has become the dominant reported location for lymphoedema care, instead of hospital-based outpatient or inpatient sites (*Table 1*). Home care and hospice increasingly were self-reported as locations to provide lymphoedema therapy services. This increase may reflect increase in health insurance reimbursement to therapists in these care settings in some countries (Schaum, 2020). Some therapists who responded to the 2018 survey also identified “other” sites beyond hospital, clinic, and

community care centres. This expansion of lymphoedema care into community settings can expand the reach of the therapist and potentially decrease the financial and employment burden on people receiving therapy services (Deng et al, 2019; Sun et al, 2020; De Vrieze et al, 2020; Blinder, 2021).

CDT remains the primary treatment modality, reflecting its continued role as the ‘gold standard’ of lymphoedema care (Armer et al, 2020; Davies et al, 2020; International Society of Lymphology, 2020). Complementary treatments such as reflexology and vibrator treatments significantly increased worldwide since 2009. Therapists self-reported that cancer-related secondary lymphoedema comprised the majority of their lymphoedema care work, primarily in the upper extremity. The surveyed therapists self-reported a percentage decrease in upper-extremity, truncal, and genital lymphoedema cases from 2009 to 2018, and therapists self-reported treating more people living with head and neck lymphoedema (*Table 1*). The self-reported treatment focus reflects current literature that recognises breast, prostate, head and neck, and gynecological cancers increasing as primary conditions often in need of lymphoedema therapy (Chaput et al, 2020).

Conclusion

This survey comparison of lymphoedema therapists characteristics and their practice settings illuminated the current practice environment and the professional characteristics of the therapists who provide care to people living with lymphoedema worldwide. The increasing need for skilled therapists in a variety of care settings is a challenge that healthcare systems and policy makers must address in order to optimise physical, psychosocial and quality of life outcomes across the lifespan. Future research should include a focus on understanding the barriers to and perceived value of advanced education beyond initial lymphoedema therapist training and the unique challenges of private practice and home care/hospice care settings to support care efforts worldwide.

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AMERICAN LYMPHEDEMA FRAMEWORK PROJECT
ALFP

Our Mission

Improve the management of lymphedema and related disorders in the United States while contributing to global international advancement.

This mission is being achieved by defining best practices of lymphedema management and developing a minimum data set to improve lymphedema outcomes. The ALFP is establishing a leadership role in lymphedema risk reduction, treatment, education, health policy and research. These outcomes are achieved through a partnership among all lymphedema stakeholders, including patients, healthcare professionals, researchers, industry representatives and third-party payers.

Among the lymphedema/lymphology organizations, the ALFP (alfp.com) has uniquely partnered with Sosido, an online knowledge exchange network for professional healthcare associations, creating community around research and practice knowledge (www.sosido.com).

Using selected search terms specific to our field, more than 3 thousand peer-reviewed articles have been retrieved for weekly email digests curated for clinicians, educators and researchers in the lymphedema field who are ALFP-Sosido members and followers. Since the ALFP-Sosido partnership

launched on October 21, 2015, this weekly digest has posted 404 publications (co)authored by ALFP steering committee members; 1,453 publications authored by ALFP members (including Steering Committee member publications); 1,459 new publications on the topic of lymphedema pulled from across all journals indexed on PubMed (the "ALFP Scan"); and 473 publications from lymphedema-specific journals (Lymphatic Research and Biology, Lymphology, and the Journal of Lymphoedema).

Interested persons may join to receive the curated publication list by completing the form at: (1) the Sosido signup form on the ALFP site: <https://www.alfp.org/sosido/> or (2) going through the Sosido signup form: <http://blog.sosido.com/join-sosido/> (in the form, one will be asked which group on Sosido s/he is interested in joining - ALFP is one of the options).

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