

Lymphoedema practice patterns: the current state of the industry

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Key words

Complete Decongestive Therapy, Intensive phase, Lymphoedema, Practice patterns, Survey

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Declaration of interest: None.

Abstract

Lymphoedema practitioners were surveyed by the Lymphology Association of North America (LANA) in 2019 to provide a snapshot of contemporary practice patterns in the management of patients diagnosed with lymphoedema and related disorders. The State of the Industry Survey respondents ($n=860$) were physical (47%), occupational (31%), and massage (12%) therapists, physical therapist assistants (6%) and other healthcare professionals. The US Midwest (35.2%) and Northeast (22.1%) geographical regions represented over half of the respondents, while 12.4% were from the West, and the remaining 26.6% were distributed among the Northwest, Southeast, Southwest, and Canada. Most (87%) of the respondents were eligible for the LANA certification examination having earned 135 or more hours of specialty training. Lymphoedema severity was rated severe (21%), moderate (41%), and mild (38%). Treatment frequency in 45% of practitioners was three times per week and 34% reported a treatment duration of 4 weeks. Significant differences in regional practice patterns were found in the time practitioners reported spending in manual lymphatic drainage, multi-layered compression bandaging, and intermittent pneumatic compression. These results will inform stakeholders about clinical practice patterns in lymphedema management.

Lymphoedema is a progressive, chronic, and debilitating condition linked to functional limitations (Lasinski et al, 2012). An accumulation of protein-rich fluid in the interstitial spaces leads to chronic inflammation and fibrosis in the affected tissue (International Society of Lymphology [ISL], 2016). Lack of standardised methods to quantify and diagnose lymphoedema contributes to difficulty in determining incidence and prevalence (Bundred et al, 2015). The US prevalence of lymphoedema is approximately 3 million (Rockson and Rivera, 2008).

Complete decongestive therapy (CDT) is the standard for conservative management of lymphoedema of any aetiology (Jeffs et al, 2018). The intensive phase incorporates daily treatments to reduce the volume and normalise tissue texture (Foldi et al, 2018). CDT includes manual lymphatic drainage (MLD), multi-layered compression bandaging (bandaging), skin care, and remedial exercises (ISL, 2016). MLD is a technique that enhances lymphatic flow, while

bandaging compresses the tissue, decreasing interstitial fluid formation and preventing dermal backflow (Moseley, 2007; Shao and Zhong, 2017). Exercise contributes to healthy body composition (Drenowatz et al, 2015) and facilitates lymphatic circulation (Suami and Kato, 2018). Patient education about skin care focuses on reducing infection risk (Jones et al, 2019). Intermittent pneumatic compression (IPC) is not a component of CDT but is utilised as an adjunct treatment with variable application and dosage (Phillips and Gordon, 2019). CDT is effective for the management of lymphoedema, especially in the earlier stages (ISL Stage I and IIa) (Table 1) (Carl, 2017). It is administered by healthcare practitioners who have earned the designation of Certified Lymphoedema Therapist (CLT). CLT represents specialty training in the management of lymphoedema. Whereas, the maintenance phase of CDT is performed by the patient to retain volume reduction (Foldi et al, 2018).

The Lymphology Association of North America® (LANA®) administered the State of

the Industry Survey (SIS). The purpose of this study was to describe the contemporary clinical practice patterns of the medical practitioners treating patients with lymphoedema and related disorders, and to inform stakeholders about current trends in practice.

LANA is a non-profit incorporated in 1999 that specialises in certifying lymphoedema practitioners. It was created in response to the 1998 American Cancer Society® Workshop on Breast Cancer Treatment-Related Lymphoedema recommendation to “establish certification guidelines to assure that specific treatments and facilities meet state-of-the-art criteria” (LANA, 2020). LANA administers a comprehensive, American National Standards Institute-accredited examination that tests the fundamental knowledge necessary to treat persons with lymphoedema and related disorders.

Methods

Survey design and development

The SIS was developed for healthcare practitioners who provide intervention

Table 1. International Society of Lymphedema Staging (ISL, 2016).

ISL stage	Description
Stage 0 (or Ia)	Subclinical state, swelling is not evident despite impaired lymphatic transport, subjective complaints present
Stage I	Early onset, accumulation of edema in the tissue that subsides with elevation, pitting may be present
Stage II	Elevation of the limb does not impact the edema, pitting is present
Late stage II	Pitting may or may not be present, fibrosis present
Stage III	Presence of hard, fibrotic tissue; pitting is absent; thickening of the skin, hyperpigmentation

Table 2. LANA geographic regions.

Geographic Region	States, district, territories, provinces and countries
Canada	Alberta, British Columbia, Manitoba, New Brunswick, Newfoundland, Labrador, Nova Scotia, Ontario, Quebec, Saskatchewan
Midwest	Iowa, Illinois, Indiana, Kansas, Ohio, Minnesota, Michigan, Missouri, Nebraska, Wisconsin
Northeast	Connecticut, District of Columbia, Delaware, Massachusetts, Maryland, Maine, New Hampshire, New Jersey, New York, Pennsylvania, Rhode Island, Virginia, Vermont, West Virginia
Northwest	Alaska, Idaho, Oregon, Montana, Nebraska, South Dakota, Washington, Wyoming
Southeast	Alabama, Florida, Georgia, Kentucky, North Carolina, South Carolina, Tennessee, Puerto Rico
Southwest	Arkansas, Louisiana, Mississippi, New Mexico, Oklahoma, Texas, Mexico
West	Arizona, California, Colorado, Hawaii, Nevada, Utah

for patients who have lymphoedema. The nineteen-question survey assessed lymphoedema management. Intensive phase data is presented in this paper, while maintenance phase data will be presented in a future paper. Survey items primarily elicited categorical data with continuous and qualitative data elicited less often. Survey items were generated and reviewed by members of the LANA Board of Directors and L&R USA.

Participants

Recruitment used snowball sampling from LANA’s electronic mailing list and social media accounts and the professional networks of the LANA Board of Directors. Additional participants were invited via the electronic mailing lists of The National Lymphedema Network, corporate sponsors of LANA, and the Wisconsin Occupational Therapy Association.

Procedures and data collection

SurveyMonkey® was used to distribute the survey instrument to participants through a direct email link for single use between February 7 and 21, 2019.

Data analysis

SPSS Statistics 23 was used for data analysis (IBM, 2019). Comparisons, parametric and nonparametric, across geographic regions were completed using descriptive statistics. Geographic regions as defined by LANA are listed in Table 2. Categorical data were collapsed when necessary to meet the assumption of chi-square analysis that all cell frequencies were greater than five (Field, 2013). The Internal Review Board of Mount Mary University approved the analysis of survey data.

Results

Characteristics of respondents

A total of 860 practitioners responded to the

survey. Physical therapists and occupational therapists represented 77.5% of respondents. Practitioners from the Midwest (35.2%) and Northeast (22.1%) represented over half of the respondents, while 12.4% of respondents were from the West, and the remaining 26.6% were distributed among the Northwest, Southeast, Southwest, and Canada. Most (87%) respondents were eligible for the LANA exam, having attained 135 or more hours of training. Referral sources were collected allowing each respondent (n=858) to contribute multiple responses (n=1826). Cancer (59%) and breast cancer centres (34%) and primary care physicians (43%) were strong referral sources. Vein (29%) and wound (25%) centres were also common sources of referrals. Table 3 describes the professions of respondents, geographic region of practice and primary referral sources.

Patient population

Respondents described their patient populations by diagnosis and severity. Thirty-three percent of patients had received previous lymphoedema treatment. Patients with primary lymphoedema were reported at a low frequency. Most (64%) respondents reported that less than 5% of their patients had primary lymphoedema and few (5%) respondents reported that 25% or more of their patients had primary lymphoedema. Respondents ranked sites of lymphoedema treated in the past year from most to least treated. In order, sites were the following: leg, arm, breast, trunk, head/neck, and genital. Lymphoedema cases by percentage severity were reported most commonly as moderate (Mean=41, Standard deviation [SD]=17) followed by mild (Mean=38, SD=22) and severe (Mean=21, SD=18) (Figure 1).

Treatment frequency and duration

Analysis of all regions determined that, during the intensive phase of treatment, practitioners most often (45%) reported treating three times per week. Twenty-five percent reported treating 5 times per week, while twice-weekly was reported by 18% of practitioners. The duration of treatment reported was 4 weeks in 34% and 3 weeks in 25% of practitioners. Two weeks were reported by 25% of practitioners, while more than 4 weeks was reported by 17% of practitioners.

Treatment frequency and duration by geographical region

Treatment frequency varied significantly

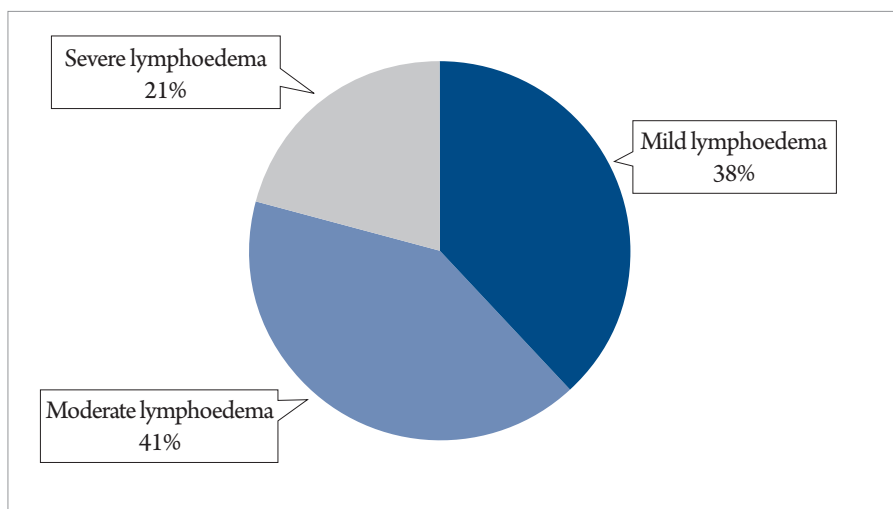


Figure 1. Lymphoedema percentages by severity.

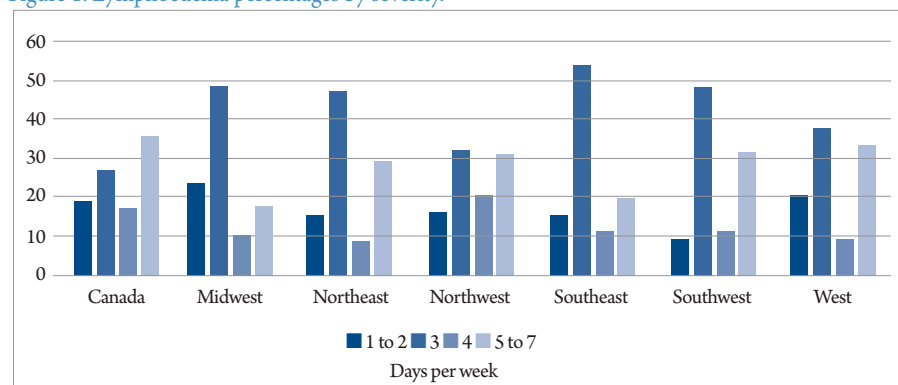


Figure 2. Intensive phase weekly frequency by geographic region.

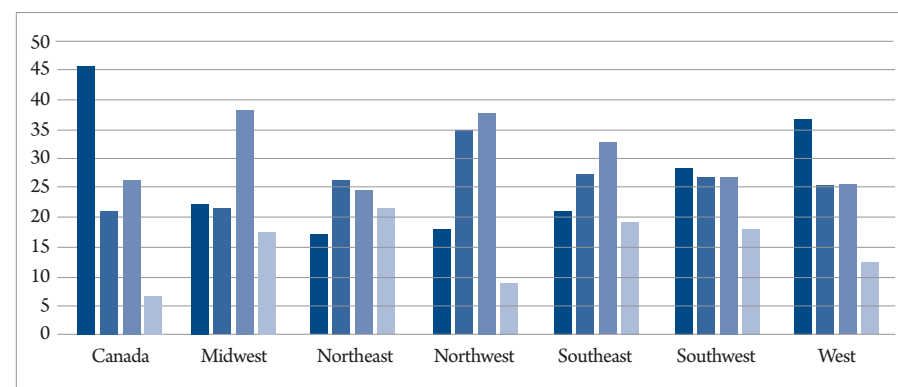


Figure 3. Intensive phase duration by geographic region.

($\chi^2[18, n=788]=41.06, P=.001$) across geographic regions. Practitioners in all regions of the US most commonly reported treating patients three times weekly during the intensive phase. Midwestern practitioners reported a frequency of one to two times per week second most commonly, while Northeastern, Northwestern, Southeastern, Southwestern, and Western regional practitioners reported five to seven times per week second most commonly. Thirty-six percent of Canadian practitioners reported treatment five to seven times per week and 28% reported three times weekly treatment. Details of other differences

between the geographic regions are illustrated in Figure 2.

Geographic region was significantly associated ($\chi^2[18, n=858]=43.73, P=.001$) with the duration of treatment. Practitioners in Canada (46%) and the West (37%) most often reported treatment durations of 1 to 2 weeks. Three-weeks duration was most common in the Northeast while 4 weeks was most reported by practitioners in the Midwest, Northwest, and Southeast. Southwestern region practitioners reported durations of 1 to 2 (28%), 3 (27%), and 4 (27%) weeks at nearly the same rate. Details

of intensive phase durations by geographic region are illustrated in Figure 3.

Interventions in an average treatment session

Overall treatment time was distributed among multiple interventions. The majority (77%) of practitioners reported spending between 15 and 44 minutes performing MLD during an average session. Bandaging time per session was reported to be between 0 and 29 minutes by 84% of respondents. Practitioners used IPC sparingly, with 72% of practitioners reporting no IPC use and 12% reporting less than 15 minutes of use. Education time per session was limited to less than 15 minutes in 39% of sessions, and from 15 to 29 minutes in 49% of sessions. Sixty percent of practitioners reported the time spent in exercise was limited to 15 or fewer minutes, while 15 to 29 minutes of exercise was reported by 30% of practitioners. Four percent of practitioners reported devoting no time to exercise. Skin care time followed a similar pattern, with 80% of practitioners reporting less than 15 minutes, 14% reporting 15 to 29 minutes, and 2% reporting no time in skin care. Percentages for all treatments and timeframes are included in Figure 4.

Interventions by geographical region

Significant regional differences were observed in the amounts of time practitioners reported engaging in three of the five surveyed treatments. MLD ($\chi^2[18, n=859]=47.167, P=0.000$), bandaging ($\chi^2[18, n=859]=35.14, P=.009$), and IPC ($\chi^2[12, n=859]=37.01, P=.001$) were significantly associated with regions. No significant associations were observed in the time that practitioners reported spending in education, exercise, or providing skin care during an average, single session.

Manual lymphatic drainage

Practitioners in all regions except for Canada most commonly reported that 15 to 29 minutes of each session was spent performing MLD. Practitioners in the Midwest and Northeast secondarily reported 30 to 44 minutes of MLD, and those in the Northwest, Southeast, Southwest, and West nearly equally reported less than 15 minutes and 30 to 44 minutes of MLD. Canadian practitioners, representing 7% of the total sample, most commonly reported spending 30 to 44 minutes and secondarily equally reported 15 to 29 and 45 to 60 minutes of each

Table 3. Characteristics of respondents (n=860).

Profession	n	%
Physical Therapist	404	47
Occupational Therapist	262	31
Massage Therapist	100	12
Physical Therapist Assistant	51	6
Certified Occupational Therapy Assistant	20	2
Other	20	2
Medical Doctor	2	<1
Total	859	
Region		
Midwest	302	35
Northeast	190	22
West	106	12
Southeast	77	9
Northwest	66	7
Southwest	60	7
Canada	57	7
Total	858	
Primary referral source (multiple responses permitted)		
Oncology/Cancer Center	505	59
Primary Care Physician	368	43
Breast Cancer Center	290	34
Venous Specialist/Vein Center	247	29
Wound Care Specialist/Wound Center	210	25
Other	128	15
Self-Referral	76	9
Physician (respondent was a physician)	2	<1
Total (respondents/responses)	858/1826	

session performing MLD. *Figure 5* provides percentages of treatment time by region.

Bandaging

Northeastern, Northwestern, Southeastern, Southwestern, and Western region practitioners most often reported not spending time with bandaging. Canadian

practitioners commonly reported less than 15 minutes of bandaging. Fifteen to 29 minutes of bandaging was most often reported by Midwestern practitioners. Reporting more than 30 minutes of bandaging was more common in the West and Northeast than in other regions. *Figure 6* illustrates bandaging time percentages by region.

Intermittent pneumatic compression

IPC use was reported infrequently in all regions. Eighty-four percent of Canadian and 43–50% of US practitioners reported never using IPC. Because of the way that the responses to this survey item were distributed, categories were collapsed to afford chi-square statistical analysis of the following categories: 0 minutes, less than 15 minutes, and 15 to 60 minutes. Seven percent of Canadian practitioners reported less than 15 minutes and 9% reported 15–60 minutes of IPC time. US practitioners reported less than 15 minutes of IPC 21–27% of the time and 15–60 minutes of IPC use 26–35% of the time. *Figure 7* illustrates IPC time percentages by region.

Discussion

The purpose of this study was to describe the contemporary clinical practice patterns of practitioners treating patients with lymphoedema and to inform stakeholders about current practice trends. This study adds to the evidence reporting variability in practice patterns. Practice guidelines and consensus documents about lymphoedema management lack agreement on treatment frequency and duration (O’Toole et al, 2013; McLaughlin et al, 2017; Davies et al, 2020). This lack of agreement may be associated with unstandardised lymphoedema diagnostic and quantification methods and the variability in study designs intended to measure the efficacy of CDT (Armer and Stewart, 2005; Bundred et al, 2015). Patients with Stage 0 lymphoedema may benefit from surveillance of limb volume and individualised exercise programmes with or without prophylactic use of compression garments (McLaughlin et al, 2017; Davies et al, 2020). Management of Stage I lymphoedema varies and may include compression garments, modified CDT, elevation, and/or exercise with or without the use of compression garments (Lymphoedema Framework, 2006; ISL, 2016; McLaughlin et al, 2017; Davies et al, 2020). CDT with or without MLD is recommended for Stage II–III lymphoedema (Lymphoedema Framework, 2006; ISL, 2016; McLaughlin et al, 2017; Davies et al, 2020). Variability in the delivery of MLD, bandaging, and IPC, as found in the SIS, may reflect unstandardised dosing recommendations for CDT.

Three surveys published in the past 10 years explored practice patterns of lymphoedema practitioners (Anderson et al, 2019; Armer et al, 2010; Polo et al, 2017). In 2010, Armer et

al described practitioner training, therapeutic interventions, and patient traits. This survey was updated in 2018 (Anderson et al, 2019). Polo et al (2017) identified the dosing of CDT for individuals with BCRL. These cohorts reported that greater than 65% of respondents completed 135 hours of training, most respondents were physical and occupational therapists, and CDT was the most common intervention (Anderson et al, 2019; Armer et al, 2010; Polo et al, 2017).

A recent systematic review of CDT reported that, in the intensive phase, daily dosing was the standard of care (Jeffs et al, 2018). However, Polo (2017) found that 95% of practitioners did not provide daily treatment, and patients with BCRL reported discordance between traditional descriptions of CDT and their treatment (Sayko et al, 2013). The SIS reported variability in dosing, with Canadian and Western practitioners being more likely to report higher treatment frequency and shorter duration (Figures 2 and 3). Current practice patterns may have been influenced by changes in the literature tailoring treatment based on the stage of the disease (Lymphoedema Framework, 2006; ISL, 2016; McLaughlin et al, 2017; Davies et al, 2020).

Significant regional differences were found in MLD, bandaging, and IPC (Figures 5, 6, and 7); however, no comparable data have been published. Canadian practitioners spent significantly more time administering MLD compared to US practitioners. Though we could speculate that Canadian and US medical systems may afford or limit practitioner autonomy for managing lymphoedema, it appears that lymphoedema care in North America has more similarities than differences. Access to lymphoedema care is limited by timely diagnosis and referral, few practitioners available for care, payor guidelines, and disparities in rural environments (Hodgson et al, 2011; Keast et al, 2015). Practitioners may place a variable priority on the time spent during MLD because of literature both questioning (Huang, 2013; Devgoodt, 2018) and promoting (Ezzo, 2015) its efficacy. IPC may have a role in lymphoedema management when used in conjunction with CDT (Feldman et al, 2012; Rogan, 2016). These findings may have influenced US practitioners more than Canadian. Lacking evidence for regional differences in time spent bandaging, we postulate that regional practice pattern differences could be tied to an individual practitioner's referral sources.

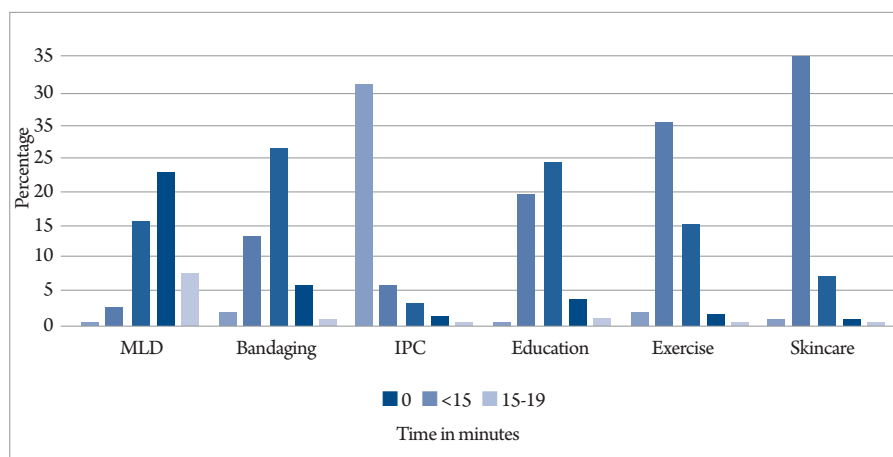


Figure 4. Lymphoedema interventions in an average treatment.

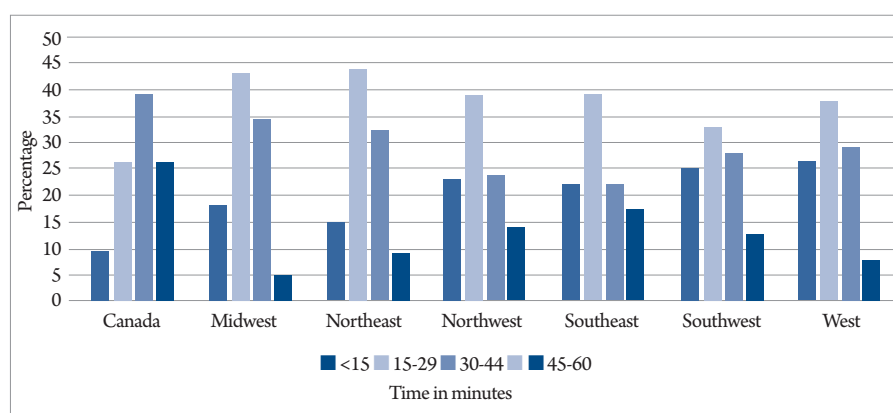


Figure 5. Percentage of MLD treatment time by U.S. and Canadian practitioners.

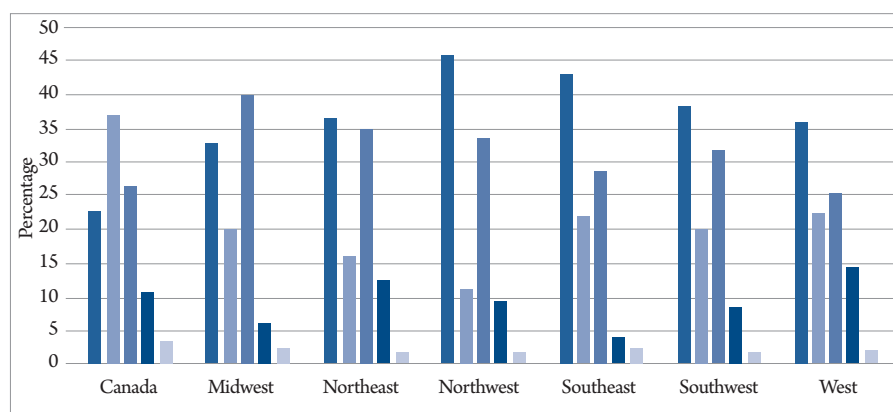


Figure 6. Percentage of multilayer compression bandaging treatment time by U.S. and Canadian practitioners.

Strengths

The SIS gained input from a large number of respondents, which provided opportunities for descriptive and comparative analysis of responses. Administration of the survey through SurveyMonkey® afforded ease of access and use, the security of responses, and the prevention of multiple submissions from the same respondent. Participants reported from all 50 states in the US and 6 Canadian provinces, possibly indicating some generalisability of findings to current practice.

Responses were analysed by geographic region, providing an opportunity to explore variations of lymphoedema treatment practice pattern differences. This analysis by geographic region affords practitioners a reference for their practice.

Limitations

This study has limitations inherent to snowball sampling. Survey respondents were able to select multiple responses and 'other' for certain items, limiting the ability to analyse

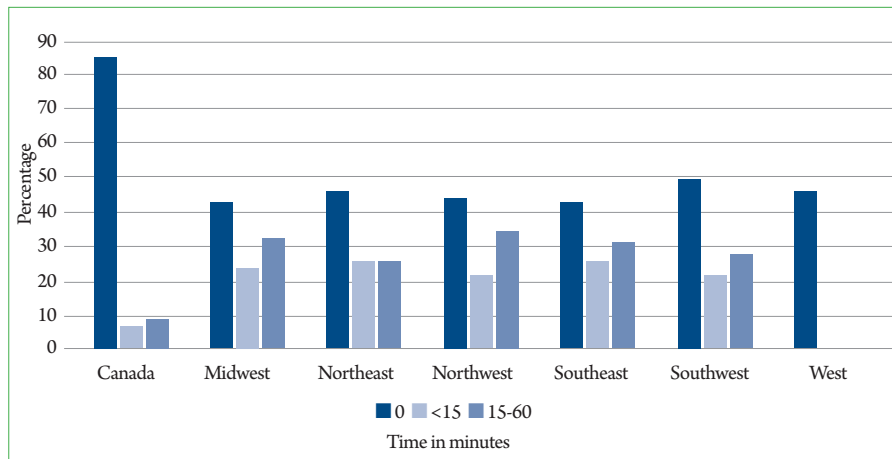


Figure 7. Percentage time per session in IPC by U.S. and Canadian practitioners.

all of the data quantitatively. Finally, the SIS was initially developed as a tool for LANA to better understand the current practice patterns versus a study tool; therefore, the survey did not undergo pretesting with experts in the field and was not validated before its use.

Conclusion

The State of the Industry Survey provides a snapshot of contemporary practice patterns in the management of patients affected by lymphoedema and related disorders. These results will help practitioners understand the current practice patterns in lymphoedema management. The variability in data affirms practitioner autonomy in planning and delivering individualised patient care. The results also reflect the variety of referral sources and associated patients. Practice patterns in MLD, IPC, and bandaging highlight the variations in the intensive phase of CDT across the regions. This paper is the first to provide specific information to stakeholders based on geographic regional patterns. A future manuscript detailing the results of the SIS related to the maintenance phase of CDT is pending.

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