A SURVEY OF LYMPHOEDEMA PRACTITIONERS ACROSS THE US

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An online survey was developed by the American Lymphedema Framework Project (ALFP) executive and research committees to assess the current scope of practice in lymphoedema treatment in the US. The analysis included responses from 415 therapists from 46 states. Respondents typically had a background in physical or occupational therapy. Nearly all reported having completed a 135-hour training course on lymphoedema treatment and management. Treatment options most often reported were comprehensive decongestive therapy (CDT), exercise/movement, risk-reduction education, and skin care.

Key words
Lymphoedema
Best practice
Skill-mix
Education

It is estimated that 22–66% of breast cancer survivors are at risk of developing lymphoedema (Petrek and Heelan, 1998; Armer and Ridner, 2007; Cormier et al, 2008; Mahamaneerat et al, 2008), a failure of the lymphatic system resulting from treatment that leads to distressing and debilitating upper limb swelling (Lymphology Association of North America [LANA], 2008). Volume reduction and symptom management by a trained lymphoedema therapist is critical to improving symptoms and quality of life during cancer recovery. Detailed information regarding therapists’ practices and management techniques is not well documented and the goal of this research survey by the American Lymphoedema Framework Project (ALFP) was to collect information about the management of lymphoedema in the US as reported by therapists.

Background

The ALFP is a national US-based collaboration of healthcare providers, researchers, patients, advocates, educators, industry representatives and third-party payers which is under the leadership of recognised clinical experts and investigators in the field of lymphoedema.

Established in 2008, the mission of the ALFP is to evaluate appropriate healthcare services for patients with all forms of lymphoedema and advance the quality of lymphoedema care both in the US and worldwide. To move this project forward the ALFP has formed a partnership with the International Lymphoedema Framework (ILF), a UK-based organisation founded in 2002 which has made significant progress in improving the management of lymphoedema in the UK and raising awareness worldwide (Morgan and Moffatt, 2006).

The main goals set forth by the ALFP in 2008 were to:

- Revise and update a best Practice Document for Lymphoedema Care in the US (Cormier et al, 2010)
- Develop and implement a lymphoedema minimum data set for national and international clinical and research use
- Design a US-based epidemiology protocol to determine the size and complexity of the problem of lymphoedema from all causes (primary and secondary lymphoedema)
- Develop methods for evaluating patient-based outcome measures and improving patient outcomes
- Develop and provide appropriate practice-based lymphoedema educational programmes
- Contribute to the mission and goals of the ILF.

During the October 2008 ALFP planning meeting, there was agreement among attendees regarding the need to assess the current scope of practice for lymphoedema treatment in the...
US since a variety of processes exist for the training of lymphoedema therapists (LANA, 2008; NLN, 2010). Practitioners also come from various specialties and training traditions. To date, there has been no large-scale study in the US examining the training and practice characteristics of lymphoedema management.

The need to better understand and improve the educational preparation of healthcare professionals caring for patients with lymphoedema also emerged as a priority during the ALFP Open Space meeting in March 2009 (Armer et al, 2009). Attendees included healthcare providers, researchers, patients, advocates, educators, industry representatives, and third-party payers and the theme was: What can be done to improve the management of lymphoedema and lymphatic disorders in the US? (Armer et al, 2009). One of the primary outcomes from the conference was a consensus on the need to establish criteria for healthcare provider education (Armer et al, 2009). Following discussion among ALFP members and meeting attendees, a web-based survey for US lymphoedema therapists was determined to be the most feasible method of assessment. The purpose of this article is to report on the results of the survey, which describe a baseline of lymphoedema therapist practice and patient characteristics in the US.

**Methods**

Between January and October 2009 the ALFP executive and research committees developed an online survey using SurveyMonkey. Milestones in the developmental process included:

- Review of overall content
- Edits and refinements through electronic review
- Beta testing of the web-based survey using 22 participants followed by review and revision
- Final survey design completed in October 2009
- Invitations sent to potential survey participants via email.

The final survey consisted of 31 items including information pertaining to therapist location, practice, training, treatments, patient characteristics, assessment methods and demographics. This study was approved by the University of Missouri Institutional Review Board.

Lymphoedema therapists were invited to complete the survey by email sent directly from the ALFP stakeholder database. Snowball sampling techniques were employed such as inviting recipients to forward the survey invitation to other eligible therapists. In addition, educators, industry partners, and other partnership organisations were asked to forward invitations to contacts on their respective mailing lists. The survey was available for completion from 4–20 November, 2009.

**Results**

Data were submitted by 415 therapists from 46 states. The majority of respondents were female (95%) with an average age of 45 years (Table 1). A descriptive summary of the data is provided, with number of responses varying from 388 to 415 for each question because participants were not required to answer all questions. All responses were analysed using Microsoft Excel software. Surveys that contained less than three answers were excluded from the analysis. Duplicate submissions were removed from analysis.

Over one-third (38%) of respondents reported practice locations in five states: Florida, Illinois, California, Texas, and New York. No responses were received from Alaska, Idaho, North Dakota and Wyoming.

**Therapist background**

The most commonly reported educational backgrounds and licences held by responding lymphoedema therapists were physical therapy (48%), occupational therapy (33%), and massage therapy (13%). Other specialties included physical therapist assistant, registered nurse, advanced practice nurse, medical doctor, certified occupational therapist assistant, and athletic trainer (collectively these represented 18% of responses). The total percentage exceeds 100% because some of the therapists held more than one licence. On average, responding lymphoedema therapists had 7.5 years (SD ± 4.75) of practice experience treating lymphoedema (Table 1).

**Therapist training characteristics**

Most lymphoedema therapists (93%) reported that they had completed over 135 hours of training consisting of one-third didactic and two-thirds hands-on tuition. Over 60% of respondents reported that they had undergone advanced training beyond 135 hours. Less than 15% held a specialisation within lymphoedema therapy and 41% reported that they were certified by the Lymphology Association of North America (LANA), which is a voluntary certification (LANA, 2008).

**Therapist practice settings**

The most common practice settings among the survey respondents included:

- Hospital-based outpatient clinic (65%)
- Private practice (26%)
- Hospital-based inpatient service (13%)
- Other practice settings, such as community cancer centres, single

**Table 1**

**Characteristics of responding lymphoedema therapists**

<table>
<thead>
<tr>
<th>Gender</th>
<th>Age</th>
<th>Years of treating lymphoedema</th>
</tr>
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<tbody>
<tr>
<td>Female</td>
<td>Mean – 45 years (SD ± 10 years)</td>
<td>Mean – 7.5 years (SD ± 4.75 years)</td>
</tr>
<tr>
<td>Male</td>
<td>Minimum – 25 years</td>
<td>Minimum – 1 month</td>
</tr>
<tr>
<td></td>
<td>Maximum – 68 years</td>
<td>Maximum – 30 years</td>
</tr>
</tbody>
</table>


96
The majority of responding therapists practice in hospital-based outpatient clinics, private practice, or hospital-based inpatient services. Treatment with CDT was reported to be available in almost all clinical settings, while other options such as exercise and risk reduction education are also provided. Respondents reported that 84% of their patients had secondary lymphoedema, while 59% had oncology-related upper extremity lymphoedema.

Conclusion
These survey findings provide evidence that a highly trained group of therapists provide care for various types of lymphoedema in a variety of practice settings in the US.

Comparison of these findings with those from a planned 2011 survey will provide an assessment of any changes in practice. This will provide an outcome measure for evaluating change in the management of lymphoedema in the US. Any future surveys should aim to contact an even wider number of therapists.

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References

Key points
- Data were submitted by 415 therapists from 46 states.
- Treatments offered by responding lymphoedema therapists were the various elements of comprehensive decongestive therapy (CDT): manual lymphatic drainage, compression bandaging, compression garments; etc.
- While the majority of survey respondents (93%) met the LANA certification training requirement, only 41% reported that they had received the voluntary certification.