American Lymphedema Framework Project (ALFP):

An Untapped Resource

Jane M. Armer, PhD, RN, FAAN, CLT

Director, American Lymphedema Framework Project

Professor, Sinclair School of Nursing,
University of Missouri
Greetings from the ALFP Steering Committee!!
A multitude of factors make 2017 the OPPORTUNE TIME for change in the field of secondary lymphedema

- Improvements in cancer detection and treatment → more survivors at lifetime risk for secondary LE
- Economic challenges → need to evaluate health resources and coverage for extended access to care
- Increased emphasis on evidence-based care
- Emergence of adjunct therapies
- Enhanced collaboration among disciplines and organizations
- Recognition of the need for consensus in measurement and diagnostic criteria
- Improved assessment tools and protocols for measurement and surveillance
As a collaboration of healthcare providers, researchers, patients, educators, advocates, and industry representatives, the ALFP will assess and promote appropriate health care services for patients with all forms of lymphedema and advance the quality of care in the United States and worldwide.
ALFP Goals 2013-17

• Update evidence-based clinical guidelines for lymphedema care in the US
• Develop and implement a lymphedema minimum data set for clinical and research use nationally and internationally.
• Serve as a national clearinghouse for lymphedema research and practice guidelines.
• Design a U.S.-based epidemiology protocol to determine the size and complexity of lymphedema from all causes.
• Develop methods and tools for evaluating patient-based measures to improve lymphedema outcomes
• Work with partners to promote health policy initiatives to improve lymphedema care in the US
ALFP: IDENTIFYING ISSUES IN LYMPHEDEMA IN THE US

Jane Attem, Joanne Harris, et al.

The American Lymphedema Framework Project (ALFP) is a national initiative introduced in 2006 to improve the management of lymphedema. ALFP is supported by the National Institutes of Health and the National Cancer Institute. The project aims to identify gaps in care and improve outcomes for people with lymphedema.

A SURVEY OF LYMPHEDEMA PRACTITIONERS ACROSS THE US

Jane Attem, Joanne Harris, et al.

An online survey developed by the American Lymphedema Framework Project (ALFP) was conducted to assess the current landscape of lymphedema management across the US. The survey aimed to identify gaps in care and improve outcomes for people with lymphedema.

ALFP TO UPDATE THE BEST PRACTICE DOCUMENT

James Attem, Joanne Harris, et al.

The Best Practice for the Management of Lymphedema was launched in 2006. It has been updated several times to incorporate new evidence and improve outcomes for people with lymphedema. The updates are based on comprehensive reviews of the literature and expert consensus.

The Best Practice for the Management of Lymphedema was updated in 2020 to incorporate the latest evidence and improve outcomes for people with lymphedema.
ALFP Goal One: Update Systematic Review on the Evidence Base for Lymphedema Practice
Literature Search (n = 5927)
Research Librarian
Hand Search

Screen 1 (n = 1303)
Review of titles & abstracts for inclusion

Screen 2 (n = 659)
Review of titles, abstracts, and full text if necessary for inclusion

Screen 3 (n = xx)
Review of full text by authors for inclusion

- PubMed
- ACP Journal Club
- PEDro
- Proceedings
- CANCERLit
- Cochrane Database & Controlled Trials
- National Guidelines Clearing House

Best Practice for the Management of Lymphoedema
International Consensus
The evidence supports the consideration of these interventions in practice. There is not yet sufficient evidence to say whether these interventions are effective or not as stand-alone therapy. The evidence indicates that these interventions are either ineffective or may cause harm.

Topic experts categorized evidence by consensus using the Oncology Nursing Society (ONS) Putting Evidence into Practice (PEP) level of evidence guidelines (Steelman et al., 2011) or other appropriate guidelines.

January 2010 Systematic Review
## ALFP Systematic Reviews

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### ALFP Systematic Reviews

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All ALFP-supported Systematic Reviews are available on [www.ALFP.org/Research](http://www.ALFP.org/Research)
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All ALFP-supported Systematic Reviews are available on [www.ALFP.org/Research](http://www.ALFP.org/Research)
Systematic reviews have been published in indexed, peer-reviewed journals matched to the focused topics (2011-14).

Summaries were published in a special issue of *Seminars in Oncology Nursing* in January 2013.
We need more **well-designed** studies

- with **precise** measurements,
- **larger** well-defined **study cohorts**, 
- followed over **longer** time periods,
- with **stand-alone** and **bundled interventions**
- incorporating **standard of care versus optimal care guidelines**.

Together, these will lead to more definitive evidence-based recommendations for the optimal management of primary and secondary lymphedema.
Prospective Surveillance Model


Best Practice Guidelines (CBCR)

Aging and Survivorship Model (TIGR)
Assessment Standards

ONS PEP publications


ALFP has partnered with Sosido to establish the ALFP Research Network, an online network of lymphedema investigators and clinicians, with the goal of creating a more connected lymphedema community, and accelerating improvements in care for patients dealing with or at risk for lymphedema.
Watch your inbox for a weekly digest:

1. New discussions in the ALFP community
2. New publications by ALFP Research Network colleagues
3. News and updates for the lymphedema community
4. Newly-released abstracts from journals you choose
ALFP Goal Two:
Development of a Minimum Data Set to Assist in International Collaborative Lymphedema Studies
The American Lymphedema Framework Project (ALFP) is building a cyber framework for minimum data set (MDS) deposit and analysis to share findings and knowledge between researchers and practitioners and to bring the latest findings to all levels of stakeholders.

Funded by National Library of Medicine

Two basic requirements:
1. Data collection must NOT be a burden for clinicians
2. There must be a SOUND REASON to collect data
Cyber Informatics Tools for Lymphedema Stakeholders

1. Minimum Data Set
   - Data Governance Protocol

2. Survey Data
   - Web Resources
   - Tools for RSS feeds
   - Tools Library
     - DCMiner, NLP tools
     - Statistics, Graphics

3. Literature Collection

4. Tools Library
   - Complex Case Library

5. Query Tools
   - Patients
   - Therapists
   - Clinicians
   - Nurses
   - Educators
   - Social workers

6. Knowledge Base
   - Best Practice Guidelines

7. ALFP Staff
   - Deposit: 1
   - Retrieve: 2, 3, 7
   - Both: 4, 5, 6.1

8. Social Worker
   - Deposit: 1
   - Retrieve: 2, 3, 7
   - Both: 3

9. Patient/Family
   - Deposit: 2
   - Retrieve: 3, 6, 6.1
   - Both: n/a

Researchers
- Deposit: 1
- Retrieve: 3, 6, 6.1, 7
- Both: 5

Clinicians
- Deposit: 1
- Retrieve: 3, 6, 6.1, 7
- Both: 3

Nurses
- Deposit: 1
- Retrieve: 3, 6, 6.1, 7
- Both: 3

Therapists
- Deposit: 1
- Retrieve: 3, 6, 6.1, 7
- Both: 3
Limb Surveillance
- Limb surveillance calculations which can be perimeter readings, circumference measurements, bioelectrical impedance, water displacement, etc.

Symptom
- Validated clinical assessment tools such as:
  - Lymphedema Breast Cancer Questionnaire (LBCQ) – swelling, heaviness, firmness, tightness, and stiffness.

Patient’s Characteristics
- Age, gender, height/weight (BMI), history, etc.
Objective Measurements:
- There are various measurement methods.
- Need to normalize for users.

Subjective Measurements:
- Different sites may ask slightly different questions pertaining to the same issue and, therefore, receive slightly different answers.
- In these cases, stakeholders will be able to aggregate similar information in the MDS to subsequently query.
Sample Queries

• Data mining
  • How do limb volume changes over time correlate with other factors, such as QOL?
  • How does development of LE following ME compare to development after other cancers?

• Decision support systems
  • How do patients best manage their LE?
  • Provide up-to-date and dynamic findings that are truly evidence-based for all stakeholders.
Findings

• Citing of findings will be reported in the aggregate and will not have individual affiliations attached.

• Findings will generate evidence-based content for the Best Practice Document and other peer-reviewed publications.
Examples of Actionable Insights

Therapists would like to see their patients’ limb volume over time and compare to patients with similar symptoms.

Researchers would like to screen limb volume data for patterns.
Concluding and Take-home Message:

Minimum Data Set (MDS)

Developing multi-layered architecture for MDS is challenging.

The knowledge gained from the MDS through data mining and analytics tools is valuable for LE risk-reduction and management.

It is not difficult to participate in this MDS initiative and the benefit to be part of the MDS is significant.
Look4LE

A Mobile App to Search Lymphedema Specialists and Provide Up-To-Date Patient-Centered Resource Analysis

Chi-Ren Shyu¹,²,³,⁴, Blake Anderson¹, Shuyu Christine Xu¹, Jane M. Armer², Gui DeSouza¹,³,⁴

¹Informatics Institute, ²Sinclair School of Nursing, ³Electrical and Computer Engineering, ⁴Computer Science Department, University of Missouri, Columbia, MO, USA
Location Search for Trained Therapists

- Search by City “Dallas, TX”
- Search by Zip Code “33136”
- Search by Current Location

Detailed Information targeting specialist
Who are eligible to be listed?

- Trained lymphedema therapists certified by:
  Lymphology Association of North America (LANA)
- 135-hour trained lymphedema therapists:
  - North American Lymphedema Education Association (NALEA)
    - Academy of Lymphatic Studies
    - Dr. Vodder School International
    - Klose Training and Consulting
    - Norton School of Lymphatic Therapy
    - Other schools approved by LANA
In the future, we plan to add MDS and Self Management Dashboard to the Mobile App

- Patient limb volume measurement history is retrieved from MDS
  - Provide visualization of up-to-date measurement trend to patients
  - Help patients with monitoring progression of LE

Take-Home Points

• Informatics tools are ready for large-scale studies

• Data are powerful for better understanding of LE community needs

• Much work needs to be done to match stakeholder’s needs to make data into actionable plans.

• We are recruiting international therapists to be included in the Look4LE directory!
LYMPHOEDEMA: Mobile Platform for at Home Observation Early-Detection and Management of LYMPHOEDEMA

Gui DeSouza¹,²,³,⁴, Kyung-min Han¹,², Guannan Lu¹,², Jane Armer³,⁴, Chi-Ren Shyu²,⁴

¹Vision-Guided and Intelligent Robotics Laboratory
²Dept. of Electrical and Computer Engineering,
³Sinclair School of Nursing
⁴MU Informatics Institute
University of Missouri, USA
Introduction

- Merits of this work
  - At home Monitoring/Management
    - Lymphedema early detection – Stage 1
  - Use of ubiquitously available games consoles and smart phones

- Importance
  - Limitations of the traditional methods for measuring limb volume
  - Rate of successful treatment vis-à-vis early detection

- Impact
  - Simple Sensors (Camera and Gyro in every off-the-shelf device today)
  - Self-management and specialist monitoring
  - Less expensive and easier to use than current methods
  - User friendly
  - Reliable
Background

Limb Volume Measurement: “gold standard”

Water Displacement

Perometry
Background

Limb Volume Measurement

Version 1.0
Background

Limb Volume Measurement

Version 2.0

Android

iPhone
Results
Results

Localized Swelling:

Pen experiment
- measured 9.2 ml
- true 11.6 ml (estimated)
- detection less than 0.5% of arm volume

Status: Beta testing and seeking clinical trials sponsorship
In Summary

• Knowledge is POWER!
  • ILF Best Practices document
  • Stakeholders meetings for prioritization of goals
  • ONS ‘Putting Evidence into Practice’ to assess study rigor
  • Systematic reviews to establish evidence base for practice
  • Rigorous prospective randomized studies to assess outcomes
  • Informatics tools to build data bases and elevate evidence
  • Mobile apps to collect data and translate findings

• ALL are about making information more readily-accessible to patients, care-givers, and policy-makers.
Acknowledgements

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- ALFP organizational support received from LE industry partners: Tactile Systems Technology, Inc; 3M; SunMED; CircAid Medical Products, Inc; Farrow Medical Innovations; Bellisse; Solaris, Inc.; Juzo; Impedimed; and Medi.

- The contribution of the ALFP steering committee in developing the ALFP mission and strategic plan.

- The ongoing support and motivational energy from our stakeholders.