



Complete decongestive therapy phase 1: an expert consensus document

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Abstract

This document was drafted by interdisciplinary experts informed by the evidence and guided by their extensive lymphedema clinical experience at the 2023 American Cancer Society (ACS) Lymphedema Summit: Forward Momentum: Future Steps in Lymphedema Management hosted by the ACS, Lymphology Association of North America, and the Washington School of Medicine in St. Louis, Missouri. Consensus statements were derived from a facilitated workshop and multiple follow-up discussions and meetings combining available evidence and clinical expertise. The consensus statements find that the essential components of complete decongestive therapy (CDT) are examination, compression, manual techniques (this may include but is not limited to manual lymph drainage), exercise, skin care, education, and self-management. Adjunctive interventions and alternatives may complement CDT. CDT should be provided by specifically trained healthcare practitioners in lymphedema management, preferably a certified lymphedema therapist. The individual's lymphedema etiology and presentation, comorbidities, and other pertinent clinical information will determine the components of CDT applied and the frequency and duration of care.

Introduction

In 1892, Alexander von Winiwater published “Die Elephantiasis” on the pathology and progression of edema and conservative treatment options. His treatment laid the groundwork for CDT, with an emphasis on skincare, elevation,

compression, exercises, massage, and patient compliance. Winiwater's concepts were advanced by Emil and Estrid Vodder in 1932, and the term manual lymphatic drainage was coined [1]. Even though several individuals or schools of thought have made slight adjustments to the individual techniques over the years, the basic components of CDT

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have remained the gold standard for conservative care for the diagnosis of lymphedema.

Twenty-five years ago, in 1998, the ACS hosted a lymphedema conference. The two primary conclusions were that there was little oversight or standardization of therapists' competency to treat lymphedema, and there was no way to identify therapists with adequate training and expertise. The main outcome of the conference was the founding of the Lymphedema Association of North America (LANA). This organization tested therapists' knowledge after they had undergone training in lymphatic dysfunctions.

As a result of enhanced knowledge of the lymphatic system and advancements in treatments, ACS and LANA organized a two-day conference in collaboration with Washington University School of Medicine in October 2023. The first day consisted of presentations on the evidence for lymphedema risk, assessment, and interventions. On the second day, all stakeholders were divided into seven groups based on areas of interest. Moderators facilitated discussions on the evidence presented and integrated it with experts' opinions to develop consensus statements. This consensus document was developed by group 5 with the purpose of identifying essential components of the decongestive phase, phase 1, of CDT for managing lymphedema based on the available evidence and skilled clinical practice. Group 5 consisted of fourteen multidisciplinary members: physicians, physical therapists, occupational therapists, massage therapists, researchers, certified lymphedema therapists, and patients with adequate training, expertise, or experience.

Consensus statements

Due to the overwhelming evidence involving breast cancer-related lymphedema (BCRL), this expert group five developed the following ten consensus statements for phase 1 of CDT for those individuals (Table 1). A separate expert group from the Summit is addressing phase 2, which focuses on volume stabilization. In this document, we acknowledge some overlap between the two phases of treatment but concentrate on phase 1. After each statement, the group provided the evidence and clinical rationale. The systematic reviews were appraised and provided quality ratings to determine the strength of the evidence. The use of the word

“should” in the statements refers to a strong obligation of a clinician to follow the recommendation. It indicates strong support for the element based both on the current evidence and expert opinion. It acknowledges that there may be occasions when the practice may not be appropriate due to patient presentation, comorbidities, or constraints. Clinicians should consider the consensus statements provided along with the individual's clinical presentation, preferences, and goals when determining an appropriate plan of care.

Gaps in the literature/limitations

The current gap in lymphedema literature is notable. Most lymphedema research focuses predominantly on cancer-related causes, with a preponderance of trials in breast cancer-related lymphedema making it difficult to generalize findings. Developing standardized terminology in clinical and research settings is critical to describing lymphedema stages and intervention components. There is a pressing need for research employing higher quality methodologies, with clear descriptors of outcome assessments, interventions, and research procedure training to provide more universally applicable insights and reproducibility. Larger, multi-site trials, with sufficient follow-up to establish long-term efficacy, are needed. Subgroup analysis from larger trials could assist in identifying the best interventions for different stages and comorbidities. Additionally, it's crucial to establish core outcomes beyond just volume reduction, encompassing the broad range of impacts of lymphedema. Understanding the degree of change needed for a clinically meaningful difference is important and should be reported for each trial outcome.

The main limitation of this consensus document was that it was developed only by a small percentage of the lymphology community. This document is meant to drive discussion, further research, and challenge the development of best practices for individuals with lymphedema.

Call to action/conclusion

This consensus calls for a unified effort to elevate the quality of lymphedema care. Facilities and clinicians are urged to integrate the ten consensus statements into their

Table 1 Consensus statements for phase 1 of complete decongestive therapy (CDT) [2–7]

- 1. Examination:** The examination is an essential component of quality care and needs to include subjective and objective assessments to determine the type and severity of lymphedema to establish an optimal individual patient-centered plan of care.
- The examination should include subjective and objective assessments. The subjective assessment should encompass a detailed medical history, symptom identification, past treatment review, patient-reported outcomes, and exploration of patient goals. Objective assessments involve precise limb measurements, tissue evaluation, joint function assessment, and, where applicable, an evaluation of lymphatic function. Findings aim to determine the type and severity of lymphedema. The development of an individualized care plan is crucial and tailored collaboratively with the patient to address their unique needs and goals. Ongoing assessment and regular adjustments are needed to optimize patient care and treatment outcomes.
- 2. Education:** Education is an essential component of effective decongestive therapy for lymphedema, with selection based on the individual's presentation.
- Based on an individual's lymphedema presentation and specific needs, educate using a patient-centered approach. Ensure individuals are empowered and well-informed about the condition and management practices. Educational content should address, but not be limited to, basic anatomy/physiology of the lymphatic system, lymphedema (e.g., causes, risk factors, risk reduction strategies, treatment), self-management, and dietary and lifestyle choices. The clinician should assess the individual's and caregiver's learning preferences and educate accordingly with regular reinforcement.
- 3. Skin care:** Maintaining the health of the integumentary system is an essential component of effective decongestive therapy for lymphedema based on the individual's presentation.
- Skin care and wound management promote integumentary health and may reduce episodes of infection. Meticulous hygiene and proactive skin care, including cleansing, hydration, debridement, and protection tailored to individual presentation, are imperative to mitigate the risk of wounds and infection. Ongoing monitoring and individualized patient education regarding infection and skin breakdown are integral to successful skin care. It is essential to address barriers to skin care management to assist individuals in performing the recommended care.
- 4. Manual techniques:** Manual techniques, which may include but are not limited to manual lymph drainage, to improve lymphatic flow and restore the health of the tissues should be considered based on subjective and objective findings as appropriate.
- While many studies have been published on volume reduction due to MLD, multiple limitations in those studies continue to restrict our understanding of its impact. Therefore, current research is inconclusive on the benefits of MLD for volume reduction as a component of CDT in the prevention of and intervention for lymphedema. Improvement in pain, tissue fibrosis, adverse conditions (e.g., axillary web syndrome, scar adherence), and quality of life have been observed with MLD, scar massage, myofascial release, and/or manual stretching. Adverse effects have not been reported for manual therapy techniques. Manual techniques to address tissue quality should be incorporated into treatment for lymphedema as appropriate. The most appropriate manual technique may or may not be manual lymphatic drainage, as clinicians should address the specific tissue dysfunctions present in an individual.
- 5. Compression:** Compression is an essential component of effective decongestive therapy for lymphedema, with products and applications based on thorough assessments of the individual's presentation.
- Compression products may include multi-layer bandaging, foam and/or padding, inelastic Velcro system, cohesive 2-layer system, and compression garment, with the selection according to the severity of lymphedema, patient comfort, and mobility. The application of compression is ideally instructed by a trained healthcare professional to ensure proper technique, including regular monitoring and adjustments as indicated to achieve the best therapeutic outcomes. Best-practice supports patients with early stage lymphedema should be fitted for a compression garment when diagnosed with lymphedema, and those with moderate- and late-stage lymphedema should have a minimum of two weeks of tailored compression involving the compression product being reapplied ideally daily until a plateau is reached and the patient progresses to the maintenance phase.
- 6. Therapeutic exercise:** Therapeutic exercise is an essential component of effective decongestive therapy in addressing dysfunctional movement patterns caused by lymphedema, stimulating the cardiovascular system, improving lymphatic flow, and enhancing overall health and fitness.
- The preponderance of evidence has been on resistance exercise, but all modes are shown to be beneficial in improving lymphatic and physical function. Modes of therapeutic exercise included in the literature are strengthening, aerobic, aquatic, and yoga during the intensive phase. Although therapeutic exercise supports lymphatic flow, the evidence is inconclusive regarding the role of exercise in volume reduction. Exercise does lead to clinically relevant improvements in overall function and quality of life. It is recommended that compression bandaging/garments be worn to increase muscle pump efficiency. Tailored, initially supervised therapeutic exercises are key in lymphedema management and should be based on each patient's specific needs and abilities.
- 7. Self-management:** Self-management should begin early in treatment with all stages of lymphedema based on individual characteristics to prepare the individual for maximal autonomy in managing the lymphedema.
- Self-management encompasses compression, exercise, skincare, self-massage (self-MLD), weight management, and risk reduction strategies. It should be tailored to the lymphedema stage and individualized according to the patient's specific characteristics, preferences, and needs. Education, support, and guidance from healthcare professionals should be readily available to maximize the patients' and caregivers' success in their self-management. Individuals should be introduced to self-management early in the treatment process to empower them and facilitate their active involvement in their care to optimize the outcomes of intensive CDT.

Table 1 (continued)

8. Frequency of treatments: Frequency and timing are essential attributes of effective CDT; moderate to severe lymphedema should be treated five days a week for at least two weeks at a minimum.

Multiple studies supported the impact of CDT on volume reduction for patients with moderate to severe lymphedema when treatment was provided five times per week for at least two weeks. The ultimate goal of CDT is the normalization of tissue and the shape of the limb. CDT should continue until this goal is met or the patient has sustained a plateau after interventions have been tailored to meet the patient's needs. CDT should be adapted as the patient progresses, and adjunctive therapies may need to be considered to achieve this goal. Five days per week is strongly recommended for a minimum of two weeks, followed by tapering of the frequency when appropriate. On rare occasions, individual patient constraints may limit the ability to participate at this frequency, which may impact the overall outcomes of therapy.

9. Healthcare training: CDT should be provided by specifically trained healthcare practitioners in lymphedema management.

Basic education on the general anatomy/physiology of the lymphatic system, pathology categories, and introductory interventions is typically provided in entry-level healthcare programs. However, advanced education of clinicians is needed to provide optimal care for this population. Advanced education should include information on anatomy/physiology, evaluation techniques, differential diagnosis, as well as the implementation of appropriate interventions, including all components of CDT and adjunctive treatments. An in-person component with hands-on practice and instructor feedback is a central part of this training.

10. Adjunctive therapy: Adjunctive therapies may be used to complement, not replace, the essential components of complete decongestive therapy for lymphedema.

Adjunctive therapies can be described as but not limited to low-level laser, intermittent compression pumps (in place of MLD), elastic taping, extracorporeal shock wave therapy, aromatherapy, reflexology, and relaxation/meditation techniques. There is insufficient evidence for these therapies in reducing volume. However, they may be associated with other benefits, such as increased well-being and decreased depression and anxiety.

practices to ensure the highest standard of care for patients with lymphedema. It is crucial that payers and administrative bodies acknowledge the importance of phase I CDT, as outlined in this consensus, and support clinicians in delivering best practices. Furthermore, the establishment of Centers of Excellence for Cancer and/or Lymphedema should hinge on integrating these consensus statements, serving as a benchmark for qualification and designation. This coordinated approach is essential for advancing care and supporting those affected by lymphedema.

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Declarations

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