



Addressing Health Care Needs for Prevention and Management of Lymphedema

The American Cancer Society has projected 1.5 million new cancer cases in 2008, and the overall cost of care has been estimated by the National Institutes of Health (NIH) to be \$206.3 billion annually. An estimated 10.5 million Americans have a past history of cancer. All cancer survivors who have surgery to remove lymph nodes and/or radiation therapy are at risk for developing the condition. Unfortunately, as many as 30% of cancer survivors have developed lymphedema secondary to the effects of their cancer treatment.

Impact on Society

Lymphedema is a debilitating progressive condition with no known cure. Patients face a lifelong struggle to manage the condition and to prevent disabling side effects and potentially lethal complications such as infection. The complex and multi-faceted causality of lymphedema makes it an expansive disease regarding age, gender, economic status, and comorbid conditions.

Primary lymphedema results from a hereditary or congenital condition whereas secondary lymphedema, the most prevalent type in the United States, is related to cancer treatment.

Primary Lymphedema

Prevalence rates for primary lymphedema have been estimated as 1.15 per 100,000 people under age 20. Congenital lymphedema is clinically evident at birth and accounts for 10%-25% of all primary lymphedema cases. Lymphedema praecox is the most common form of primary lymphedema, accounting for 70%-80% of all primary cases. By definition, the onset occurs before age 35 affecting females 4 times as often as males.¹

Secondary Lymphedema

Incidence rates for secondary lymphedema range from 24% to 49% for breast cancer-related lymphedema after mastectomy, from 4% to 17% after sentinel lymph node biopsy with radiation²⁻⁹ and 5% to 67% for pelvic cancers.¹⁰⁻¹³ Reported lower limb lymphedema incidence rates after gynecological and urogenital cancer range from 50% to 80%.^{14,15} Incidence rates among patients treated for melanoma range from 40% to 75%.

The societal impact of lymphedema is significant, considering not only those diagnosed with this lifelong condition, but also those who are at risk for developing the disease. The American Cancer Society has projected 1.5

million new cancer cases in 2008, and the overall cost of care has been estimated by the National Institutes of Health (NIH) to be \$206.3 billion annually.¹⁶ An estimated 10.5 million Americans have a past history of cancer.¹⁶ All cancer survivors who have surgery to remove lymph nodes and/or radiation therapy are at risk for developing the condition. Unfortunately, as many as 30% of survivors have developed lymphedema secondary to the effects of their cancer treatment.

What Happens to Individuals With Lymphedema

The underlying cause of lymphedema is lymphatic system dysfunction which results in an abnormal protein rich swelling in the tissue. If left untreated, lymphedema can progress to a substantial, often unsightly size.¹⁷ The protein-rich nature of the fluid has dangerous implications for the patient as it predisposes them to recurrent tissue infections and leads to hardening of the tissue and elephantiasis.^{18,19}

These marked changes in the limb often lead to disabling impairments such as joint dysfunction, muscle weakness, altered ambulatory capacity, and pain.²⁰⁻²² The psychological and psychosocial implications can be devastating as patients struggle to find clothes to fit their uneven limbs, experience difficulty completing their activities of daily living, and even remove themselves from social surroundings out of embarrassment at this unsightly condition.^{23,25}

The Physical Therapist's Role in Assessment and Treatment

The role of the physical therapist is vital to the early detection, treatment, and long-term management of lymphedema. Physical therapist interventions can diminish the accumulation of fluid in the limbs and generate great functional gains.²⁶⁻²⁹

It is essential that patients with lymphedema have access to physical therapists to manage, in collaboration with their physician, lymphedema at any stage of the disease. Currently, newly diagnosed cancer patients with solid tumors progress through three levels of primary care—surgery, chemotherapy, and radiation therapy—focusing on ablation of the disease with limited attention to comorbidities associated with these therapies.

In many cases, primary health care providers may not diagnose lymphedema until the condition is visibly apparent or until the degree of dysfunction and impairment is so severe that patients can't function at home or work. While medicine has promoted early detection and

treatment of cancer from the perspective of a disease model of care, it has failed to adequately address lymphedema in the same prospective, proactive fashion.³⁰ The role of the physical therapist is ideally as a primary provider for surveillance, early detection, and management of the condition. Only when lymphedema is detected at its earliest onset can the condition be prevented from progressing to a more advanced stage. Pre-operative assessments of patients are important to establish a baseline and monitor for lymphedema.³¹

A patient with a clinical diagnosis of lymphedema should routinely be referred to a physical therapist to undergo an intensive phase of complete decongestive therapy. This consists of manual lymph drainage, compression bandaging, exercise, extensive education, and custom compression garments in an effort to restore near-normal limb girth. Patients generally achieve significant reduction in limb volume, improved cosmesis, softening of tissue and return to near normal function through a physical therapist's intervention.

However, even with successful decongestion of the swelling, the lifelong nature of the condition warrants a daily arduous maintenance routine that the patient must adhere to. This becomes exhausting and frustrating, often leading to noncompliance and relapse of the condition.³²⁻³⁴ Ongoing, periodic episodes of care are needed with the physical therapist to ensure appropriate self-care and comprehensive disease management.

Current Policy Challenges

Consumer and Provider Awareness

Lymphedema is a common condition following cancer treatment; however, often it still goes undiagnosed and untreated. Recognition of the condition sometimes results in referral to physical therapy, but deficits in health care provider awareness of what lymphedema is and how it is treated often result in an inadequate treatment plan.

Patients would benefit by identifying physical therapists as the **primary providers** of services directed at reducing the severity of comorbidity and impairments, restoring function, and promoting higher levels of quality of life among cancer survivors.

Direct Access to Physical Therapy for Medicare Beneficiaries

APTA strongly supports improving access to physical therapist services for all patients, including those with lymphedema. The Medicare Patient Access to Physical

Therapists Act would allow Medicare beneficiaries to directly access physical therapists for outpatient services as authorized by state law. This legislation would eliminate Medicare's burdensome requirements to access a physical therapist's services. As has been noted, too often patients with lymphedema go undiagnosed until their degree of dysfunction and impairment is so severe that they no longer are able to function at home or work. Physical therapist intervention can help patients restore function and improve their quality of life.

The Medicare Patient Access to Physical Therapists Act has had the endorsement of several patient and provider groups including the American Physical Therapy Association, National Rural Health Association, Easter Seals, American College of Rheumatology/Association of Rheumatology Health Professions, and American Academy of Orthopedic Manual Physical Therapists. Improved access to physical therapist services would allow beneficiaries to receive timely care as they learn to manage this lifelong condition.

Repeal of the Medicare Therapy Cap

Physical therapist intervention has been shown to improve functional outcomes and reduce disability in people with lymphedema.²⁶⁻²⁹ Patients with lymphedema require multiple physical therapy visits and periodic episodes of care. Currently Medicare coverage has an arbitrary financial limit or "therapy cap" on outpatient rehabilitation services. Repeal of this Medicare therapy cap is needed to ensure that beneficiaries receive appropriate and timely care to maximize function and independence.

Current Funding Challenges

Reimbursement for Services

Individuals with lymphedema may experience negative financial ramifications associated with treatment. Many of the modes of treatment, which are medically indicated to treat the condition, are not reimbursed by payers, including Medicare. The out-of-pocket costs can be substantial for a patient. Coverage for physical therapist services related to lymphedema is limited, and a change to the reimbursement structure is needed. Limitations on the number of physical therapy visits can have a detrimental impact on those with the most severe form of the disease, lymphostatic elephantiasis. Partial coverage for treatment and supplies creates barriers for the patient including delays in treatment initiation and completion.

Assessment prior to surgery of all cancer patients is

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also needed. Currently there is no method to reimburse physical therapists for screening procedures under federal or private insurance plans. Medicare does not pay for compression garments which are medically necessary for lymphedema patients that are unable to adequately maintain their lymphatic flow. Without these vital items, patients are unable to adequately manage their limb volume, which results in exacerbations of swelling, costly infections and hospital stays. Garment costs can average over \$2000 per year in out of pocket expenses for the patient. Many patients delay their treatment or are unsuccessful in managing their condition because they lack access to compression garments.

Research Funding

NIH funding of extramural research trials has typically been the greatest source of research dollars available for new or existing research for US institutions and universities. Success rates for grant applications have declined over past years due to a restructuring of national priorities requiring many researchers to apply for non-government grants through private, professional, and industrial organizations. In addition, funding of research concepts related to function, quality of life, and productivity of cancer survivorship is among the least funded by both federal and nonfederal sources.

APTA supports increasing the NIH research budget. Investment in and recognition of rehabilitation within NIH and other federally funded research entities is a necessary step toward continuing to meet the needs of individuals in our population who have chronic disease, developmental disabilities, or traumatic injuries. APTA is pursuing legislation, regulations, and other policies to secure and improve federal funding for rehabilitation research conducted by physical therapists.

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Additional Web Resources:

National Lymphedema Network, www.lymphnet.org

National Institutes of Health, <http://www.cancer.gov/cancertopics/pdq/supportivecare/lymphedema/HealthProfessional/page2>

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