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REVIEW

Beyond Swelling: Redefining Head and Neck Lymphedema through Surveillance and Prevention

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Abstract

Purpose of Review Head and neck lymphedema (HNL) is a common early and late effect of head and neck cancer treatment that can involve both external tissues and internal pharyngeal and laryngeal structures, yet is frequently under-recognized. This review summarizes contemporary evidence on epidemiology, mechanisms, assessment, functional impact, management, and prevention-oriented surveillance.

Recent Findings When systematically assessed, particularly with routine endoscopy, HNL is identified in the majority of survivors (approximately 70% to >90%, depending on methods), and severity correlates with dysphagia, voice impairment, airway symptoms, and reduced quality of life. Complete decongestive therapy remains first-line management and improves external edema in many patients, while emerging modalities (advanced pneumatic compression, photobiomodulation, and microsurgical reconstruction) show early promise but require higher-quality evaluation.

Summary Integrating systematic assessment and timely rehabilitation intosurvivorship care may improve functional outcomes, while acknowledgingongoing evidence gaps.

Keywords Head and neck cancer · Lymphedema · Survivorship · Dysphagia · Rehabilitation · Surveillance

Introduction

Improved survival in head and neck cancer (HNC) has brought late effects into sharper clinical focus [1, 2]. Head and neck cancer–associated lymphedema (HNC-AL), a form of secondary lymphedema affecting external (face/neck) and internal (pharynx/larynx) tissues, arises following cancer-directed treatments such as neck dissection and/or radiotherapy, yet is often overlooked despite high prevalence and significant functional consequences [3, 4]. Hereafter, we use the term head and neck lymphedema (HNL) to refer to head and neck cancer–associated lymphedema unless otherwise specified.

Primary HNL appears uncommon compared with cancer-related disease; contemporary cohorts and claims-based studies almost exclusively describe lymphedema as a treatment sequela in HNC survivors, whereas primary craniocervical lymphedema represents a small minority of cases encountered in clinical practice. Robust epidemiologic estimates for primary HNL are lacking, as most available data focus on secondary lymphedema after cancer therapy.

Early prospective work established that nearly three-quarters of HNC survivors exhibit HNL when systematically assessed, with many demonstrating both internal and external components [5]. In early cohorts relying primarily on clinical examination without routine endoscopic surveillance, HNL was identified in approximately three-quarters of HNC survivors; later studies incorporating systematic

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endoscopy revealed substantially higher internal edema prevalence. Building on this foundation, subsequent studies tied edema severity to symptom burden and quality-of-life decrements [6]. More recent prospective cohorts incorporating routine endoscopic assessment have demonstrated even higher prevalence, underscoring how frequently internal HNL may be missed in standard clinical follow-up [7–10]. Despite its prevalence, HNL has historically received less attention than other late effects of HNC therapy, in part because of the absence of standardized assessment tools and limited awareness among treating clinicians, including surgeons, oncologists, and rehabilitation specialists.

Epidemiology and Natural History

Prospective cohorts report external edema in up to ~ 90% and internal pharyngo-laryngeal edema in up to ~ 97% of HNC survivors when routine endoscopic screening is incorporated [7–11].

In a prospective cohort of HNC survivors assessed ≥ 3 months after treatment using standardized clinical and endoscopic criteria, 75.3% were found to have lymphedema, with 10% demonstrating external involvement only, 39% internal involvement only, and 51% combined disease [6]. Prevalence peaks in the early months, reaching roughly 80% at three months, and declines modestly by nine to twelve months, with internal edema persisting longer than external in many patients [12]. Higher nodal burden and combined-modality therapy are repeatedly associated with HNL, consistent with greater lymphatic disruption [12].

Pathophysiology and Risk Factors

Surgery and irradiation injure collecting lymphatics/nodes, causing protein-rich fluid stasis that triggers chronic inflammation, adipose deposition, and fibrosis, progressing from soft, pitting edema to firm, less reversible swelling if untreated [13]. This inflammatory cascade, well described across secondary lymphedema syndromes and supported by observational data in head and neck cancer survivors, may perpetuate lymphatic injury over time, thereby contributing to progressive fibrosis and associated symptoms such as dysphagia, dysarthria, and pain. Once established, this process often evolves into a chronic condition; although severity may fluctuate, most patients require ongoing self-management and periodic therapeutic support to maintain control and prevent further progression. Treatment-related predictors include the extent of neck dissection (greater node removal, higher risk) and radiation dose/volume to nodal levels; modeling studies corroborate dose–volume effects on HNL risk [12, 14]. Patient factors such as higher body mass index (BMI) and low physical activity further increase odds of clinically significant edema in observational cohorts [12, 15].

Diagnosis and Staging

Clinical examination remains the cornerstone of diagnosis. External head and neck lymphedema typically manifests as diffuse, fluctuating swelling of the face or neck accompanied by a sensation of heaviness, tightness, constriction, or congestion, whereas internal lymphedema presents with symptoms such as globus, dysphonia, and dysphagia [16, 17]. Flexible endoscopic assessment of the pharynx and larynx provides the most reliable means of detecting internal disease, and systematic incorporation of endoscopy into survivorship follow-up was pivotal in establishing the true prevalence of internal edema [5, 18]. Equally important, structured surveillance requires collection of baseline data, ideally pre-treatment or early post-treatment, to permit meaningful comparison over time and to identify early, subclinical changes that might otherwise be missed. For external lymphedema, the MD Anderson Cancer Center (MDACC) Head and Neck Lymphedema Scale represents the most widely adopted framework, adapting the traditional Földi grading system to capture the full spectrum of disease from reversible pitting edema to irreversible fibrotic change [19]. For internal lymphedema, the Revised Patterson Edema Scale has shown moderate to substantial inter-rater reliability across subsites, including the supraglottis and pharynx, and is increasingly used to standardize both clinical evaluation and research reporting [20].

Although computed tomography (CT) and ultrasound are promising adjuncts for diagnosis and longitudinal monitoring, no single modality is fully validated across the spectrum of HNL presentations [21, 22]. The Revised Patterson Edema Scale and the Lymphedema and Fibrosis Scale for Head and Neck demonstrate acceptable reliability, yet neither provides a comprehensive standard capable of capturing all external and internal disease manifestations [18]. Another complementary modality that has gained recent attention for detecting and surveilling both external and internal lymphedema is fluoroscopy, specifically, quantitative measurements obtained from the scout image during a videofluoroscopic swallow study. These include posterior pharyngeal wall thickness as well as velar and epiglottic width and the hyoid-to-skin distance [23, 24].

However, no universally accepted gold standard for HNL assessment exists. While clinical examination and flexible endoscopy are indispensable, early or subtle changes may be missed, particularly in the absence of structured staging and baseline comparison. Recent systematic reviews

support a multimodal approach that integrates clinical and endoscopic assessment with objective imaging (e.g., CT when clinically indicated and ultrasound for serial monitoring) and validated patient-reported outcome measures to capture symptom burden [21]. Substantial international practice variation in both diagnostic assessment and conservative management has been documented in recent Delphi studies, underscoring the need for consensus-based frameworks and further validation of existing assessment tools to harmonize care [25].

Functional Impact: Swallowing, Speech/ Voice, Airway, Quality of Life

The severity of both internal and external lymphedema is directly correlated with greater symptom burden, reduced functional status, and diminished quality of life [3, 6, 15]. In cross-sectional analyses, higher composite edema scores were associated with dysphagia, dysphonia, pain, fatigue, and lower disease-specific quality-of-life ratings [6]. Internal pharyngeal and laryngeal edema impairs bolus propulsion and increases the frequency of penetration and aspiration events on instrumental swallowing assessment, whereas external edema and associated tissue induration contribute to altered speech resonance and restricted cervical range of motion [6, 26, 27]. Although frank airway compromise is uncommon, marked supraglottic edema may exacerbate sleep-disordered breathing and, in select patients, complicate airway management during intubation [6].

In addition to functional impairments, HNL carries a substantial psychosocial burden. Patients frequently report changes in body image, heightened anxiety, and social withdrawal. Barriers to timely therapy, such as delayed recognition, limited access to trained therapists, and financial constraints, further compound these challenges [28–30]. Existing generic quality-of-life instruments may underestimate the true impact of HNL, underscoring the need for validated, lymphedema-specific patient-reported outcome measures.

Development and routine use of head-and-neck–specific quality-of-life measures are therefore a priority, as generic instruments may underestimate the clinical and psychosocial burden of lymphedema [31, 32].

Management: Conservative

The standard of care for HNL is complete decongestive therapy (CDT), a multimodal regimen consisting of manual lymphatic drainage, compression using garments or bandaging adapted for the cranio-cervical region, therapeutic exercise, and meticulous skin care [33]. In the largest reported single-center series, encompassing nearly 1,200 patients with evaluable outcomes in 733, approximately 60% demonstrated objective improvement in edema staging or measurement after participation in a head-and-neck–specific CDT program [19]. These findings underscore the real-world effectiveness of CDT and highlight the importance of adapting traditional limb-based protocols to the anatomic complexities of the head and neck.

A 2019 systematic review of lymphedema following HNC therapy found that CDT, comprising manual lymphatic drainage with or without adjunctive compression and exercise, was associated with reductions in edema and symptom burden; however, most included studies were small and heterogeneous, limiting firm conclusions about efficacy [13]. A more recent systematic review of rehabilitation interventions for HNC-AL, including advanced pneumatic compression devices and adjunct modalities such as kinesio taping, supports that these interventions are safe and may be beneficial, though higher-quality evidence is still needed to define optimal protocols [34].

Initiating therapy at an early stage yields the most favorable and reversible outcomes, whereas delayed intervention increases the likelihood of progression to fibrosis. Sustained benefit depends on consistent adherence to daily self-care, including manual drainage and prescribed exercises. Compression strategies, while essential for long-term control, must be carefully adapted to balance therapeutic efficacy with comfort and cosmetic acceptability to ensure patient compliance [13].

Nevertheless, the strength of evidence for conservative therapy remains limited. While physical therapy, manual drainage, compression, and exercise have demonstrated consistent benefit for external lymphedema, durable improvement in internal edema has not yet been demonstrated in high-quality longitudinal trials. Importantly, this gap likely reflects an absence of rigorous evaluation rather than a demonstrated lack of benefit, as few interventions have been systematically studied for internal edema using validated measures. Emerging modalities such as photobiomodulation have shown feasibility and preliminary benefit in pilot studies, but require confirmation in larger randomized trials before routine clinical use can be recommended [35, 36].

Adjuncts and Emerging Therapies (Table 1)

Advanced pneumatic compression devices have been evaluated in a randomized, wait-list controlled trial, in which twice-daily home use over eight weeks led to measurable reductions in visible external edema and greater patient-reported control compared with standard self-care, with a

Table 1 Interventions for head and neck lymphedema

Intervention	Evidence base	Outcomes	Notes
Complete Decongestive Therapy (CDT)	Largest series ($n \approx 1200$), observational cohorts	Reduced swelling, improved function	Requires adaptation for head/neck anatomy
Advanced Pneumatic Compression	RCT (external edema); proof-of-concept internal response; single vs. multiple session studies; longitudinal PROM data	Reduced external edema; immediate internal + external response; improved symptom burden and self-management	Evidence suggests greater response with repeated sessions; promising modality for internal edema
Photobiomodulation	Pilot and feasibility studies	Reduced swelling, improved patient-reported outcomes	Needs randomized controlled trials
Elastic kinesio taping	Small observational studies; included in systematic reviews	Modest edema reduction; symptom relief	Adjunctive therapy; limited and heterogeneous evidence
Surgical (LVA, robotic-assisted)	Case series	Reduced edema staging; improved quality of life	Feasible in selected refractory cases; needs registries
Psychosocial support	Narrative and systematic reviews	Reduced anxiety; improved coping	Often underutilized

This table summarizes conservative, device-based, surgical, and psychosocial interventions for head and neck lymphedema, outlining the current level of evidence, reported outcomes, and considerations for clinical application

favorable safety profile [37]. Although the sample size was small, improvements were noted in symptoms including heaviness and tightness. Gregor and colleagues reported that a single session of external advanced pneumatic compression produced statistically significant reductions in both internal (pharyngeal and laryngeal) and external edema, providing important proof-of-concept evidence that internal lymphedema may be amenable to pneumatic compression [23]. In complementary work, Gutierrez and colleagues demonstrated that treatment with advanced pneumatic compression devices was associated with clinically meaningful improvements in head and neck lymphedema, with greater response observed after multiple treatment sessions compared with a single session [38]. Longitudinal follow-up further showed sustained improvements in patient-reported outcomes related to symptom burden and self-management, supporting feasibility and durability of benefit in cancer-related head and neck lymphedema [39]. Together, these findings underscore the promise of pneumatic compression not only for chronic external swelling but also as a unique intervention for internal edema. Early microsurgical experience with lymphovenous anastomosis in refractory cases has demonstrated improvements in staging on the MDACC scale and reductions in symptom distress scores at approximately one year of follow-up, suggesting feasibility and potential benefit in carefully selected patients after adequate recovery from radiation [40, 41]. Additional modalities, including low-level laser therapy and targeted debulking procedures such as submental liposuction, have shown supportive results in small series and pilot trials [13]. Pharmacologic approaches, including selenium supplementation and anti-fibrotic or anti-inflammatory agents, remain investigational, and no pharmacologic therapy is currently established as standard of care [13].

Screening and Survivorship Integration (Table 2)

Because early-stage edema is more amenable to reversal, many survivorship programs incorporate structured surveillance into routine post-treatment follow-up [42, 43]. Importantly, the NCCN Survivorship Guidelines now acknowledge lymphedema as a recognized late effect and support referral for evidence-based management, including complete decongestive therapy and advanced pneumatic compression [42]. A comprehensive surveillance pathway includes systematic inspection and palpation for external swelling, directed review of lymphedema-related symptoms, and routine flexible endoscopic evaluation, supplemented by fluoroscopic measurements where available, regardless of whether internal edema is clinically suspected [5, 42, 43]. Baseline data collection, ideally obtained pre-treatment or early post-treatment, is essential to allow meaningful comparison over time and to identify subtle or mild edema that might otherwise be overlooked. Foundational prevalence studies emphasized the importance of endoscopic assessment for detecting late-effect lymphedema during standard survivorship visits, with prompt referral for therapy when identified [5]. Nevertheless, large claims-based analyses indicate that lymphedema remains substantially under-recognized and undertreated at the health system level, underscoring the

Table 2 Comparative features of head and neck vs. Breast Cancer–Related lymphedema

Domain	Head & Neck Lymphedema (HNL)	Breast Cancer–Related Lymphedema (BCRL)
Primary sites	Face, neck, pharynx, larynx	Arm, chest wall
Prevalence	70% to >90% when systematically assessed (varies by method; internal edema higher with routine endoscopy)	20–40% of breast cancer survivors (depending on treatment)
Key risk factors	Neck dissection, nodal radiation, high BMI, multimodality therapy	Axillary node dissection, radiation, infection, obesity
Functional impact	Dysphagia, dysphonia, airway obstruction, reduced ROM, psychosocial distress	Arm swelling, heaviness, pain, reduced ROM, functional limitation
Detection tools	Clinical exam, endoscopy, MDACC scale, Revised Patterson scale, fluoroscopy with specialized software	Limb circumference, perometry, BIS
Prevention evidence	Emerging, limited to observational data	Strong evidence from prospective surveillance and BIS cohorts
Established guidelines	No HNL-specific standardized protocol; survivorship guidance emphasizes late-effect assessment	ASCO, NCCN endorse surveillance and management pathways

This table contrasts the epidemiology, clinical features, risk factors, functional consequences, detection methods, prevention evidence, and guideline status of head and neck lymphedema compared with breast cancer–related lymphedema, highlighting key parallels and differences

need for formalized screening protocols within survivorship care pathways [4].

Breast cancer–related lymphedema literature supports prospective surveillance with early intervention to reduce progression and severity, providing a rationale to consider analogous prevention-oriented models in HNC survivorship. In a meta-analysis of randomized and observational studies, prospective surveillance with early management was associated with around 69% reduction in risk of chronic lymphedema compared to standard care (RR 0.31, 95% CI 0.10–0.95) [44]. In a large observational cohort using bioimpedance spectroscopy (BIS) monitoring, the early surveillance group (initiated preoperatively or within 90 days post-surgery) demonstrated substantially lower rates of clinical lymphedema (14% vs. 39%) and fewer cases of stage II–III disease (4% vs. 24%) compared with traditional referral pathways [45]. Furthermore, a randomized trial combining a prospective surveillance model with supervised multimodal exercise in high-risk breast cancer patients showed significant reductions in limb volume and improvements in strength and quality of life [46]. While direct evidence that prospective surveillance reduces chronic HNL is currently limited, these data support extrapolation of a prevention-oriented framework for HNC survivorship, emphasizing earlier detection and timely referral.

Research Gaps and Future Directions

Several important knowledge gaps and priorities for future research in head and neck lymphedema remain. First, high-level evidence from randomized or comparative-effectiveness trials is needed to evaluate existing and emerging treatment strategies, including complete decongestive therapy, pneumatic compression devices, and other conservative or device-based interventions. Such studies should ideally be multicenter and incorporate functional and quality-of-life endpoints in addition to anatomic measures. Second, there is a critical need to develop and evaluate targeted therapies for internal lymphedema of the pharynx and larynx, for which effective interventions remain limited. Third, prevention-oriented strategies warrant investigation, including predictive models that integrate surgical extent and radiation dose to identify patients at highest risk who may benefit from early diagnosis and proactive rehabilitation. Fourth, future studies should define the optimal duration and intensity of treatment, characterize treatment effects over time, and assess the cost-effectiveness of long-term lymphedema management, to support implementation within survivorship programs and justify systematic integration of lymphedema care. Finally, microsurgical interventions such as lymphovenous anastomosis require further study, with prospective registries needed to clarify optimal patient selection, timing relative to radiation recovery, and the durability of clinical benefit.

In addition, future research should prioritize the development of validated, lymphedema-specific quality-of-life instruments and incorporate psychosocial outcomes into study design. Integration of multidisciplinary survivorship care models, including oncology, rehabilitation, speech pathology, and psychosocial support, will be essential to address both the physical and emotional sequelae of head and neck lymphedema.

Conclusion

HNL is a common and morbid sequela of HNC therapy, yet may be improved when identified early. Systematic assessment, particularly with targeted endoscopic evaluation, has clarified that disease burden is higher than historically recognized and may facilitate earlier initiation of conservative management. Complete decongestive therapy remains first-line treatment and improves external edema for many patients, while device-based and surgical approaches show early promise in selected refractory cases but require

stronger comparative evidence. Given its functional and psychosocial impact, incorporating structured HNL assessment and timely referral into survivorship care is reasonable, while acknowledging that prevention-oriented surveillance strategies are informed partly by extrapolation from breast cancer–related lymphedema literature and that high-quality data, especially for internal edema, remain limited.

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Data Availability No datasets were generated or analysed during the current study.

Declarations

Ethical statement This review did not involve human participants, patient data, or animal subjects. All information presented was obtained from previously published, peer-reviewed literature. Institutional review board approval and informed consent were not required.

Competing interests The authors declare no competing interests.

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