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ORIGINAL ARTICLE

Treatment approaches and outcomes of a head and neck lymphedema service at an Australian comprehensive cancer center

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Abstract

Background: Patients treated for head and neck cancer are at high risk of developing head and neck lymphedema (HNL). We describe outcomes of HNL management at an Australian institution from 2018 to 2020.

Methods: Electronic records from Chris O'Brien Lifehouse were retrospectively reviewed from January 1, 2018 to December 31, 2020. Objective changes in HNL were assessed using The M. D. Anderson Cancer Center (MDACC) HNL rating scale and Assessment of Lymphedema of the Head and Neck (ALOHA).

Results: Among the 100 patients referred for management of HNL, surgery was the most frequent treatment modality (80%; 70% with neck dissection) and 69% underwent radiotherapy. Manual lymphatic drainage (MLD) was most often prescribed (96%), followed by self-MLD (93%). Small but significant improvements in ALOHA measurements were observed for 50 patients (50%). Only 5/29 (17%) patients had post-treatment improvements on the MDACC scale.

Conclusions: Standardized, prospective measurement of treatment approaches and outcomes is needed to further evaluate the service.

KEYWORDS

exercise, head and neck cancer, lymphedema, self-management, supportive care

1 | INTRODUCTION

Lymphedema is a complex, chronic, and progressive condition that can have an immense burden on patient well-being, function, and quality of life. Lymphedema may arise following cancer treatment involving surgery and/or radiotherapy, because the lymphatic structures and surrounding soft tissues are disrupted, resulting in deranged lymph transport,[1] and ultimately abnormal tissue pliability and swelling.[2] The head, neck, and face contain a large network of lymphatic tissue which may be affected by direct tumor infiltration, surgical resection of the tumor and surrounding tissues, and radiation injury.[3–5] Consequently, lymphedema can manifest externally (swelling of the soft tissues of the face) or internally (swelling of the soft tissue structures in the oral cavity, pharynx, and larynx).[6] If left untreated, head and neck lymphedema (HNL) can result in disfigurement, loss of critical functions (airway compromise, difficulty swallowing and vocalizing[7]), decreased range of motion, abnormal posture, musculoskeletal discomfort, and altered quality of life.[8,9]

The reported incidence of lymphedema among patients recovering from head and neck cancer (HNC) varies widely in the literature, ranging from 12% to 98%.[10,11] Body image distress has been reported in 13%–20% of patients with HNC,[12] with significant impact on a patient's ability to eat and talk in public, work, and engage in other activities. Withdrawing from public and social setting means HNC survivors can be disengaged in help-seeking and be unable to advocate for themselves, resulting in loneliness, poor quality of life, and physical and social–emotional functioning,[13] especially for those with limited social support.[14] In addition to the disfiguring effects of external HNL, internal lymphedema has recently been identified, frequently co-occurring with external lymphedema.[15] Internal HNL involves the anatomy of the mucosal lining of the oral cavity, pharynx, and larynx, whereas external HNL involves the more visible regions of the head and neck.[16] While more readily identified, external HNL was reported to be less prevalent than internal HNL in a recent study by Jeans and colleagues.[11] Their cross-sectional survey of 62 patients who were one to 3 years post-HNC treatment found that 37% of patients had external lymphedema and, alarmingly, 97% of patients had internal lymphedema, essentially hidden from view.

Lymphedema requires holistic and multidisciplinary management.[17] Complete decongestive therapy (CDT) aims to reduce swelling, improve condition of the skin and tissues, and increase mobility by mobilizing lymph and dissipate fibrosclerotic tissue.[18] CDT involves several sessions with a lymphedema therapist, with the goal of having the patient be able to self-manage as quickly as possible. While some patients are able to achieve this goal, others have high levels of discomfort or swelling, reduced range of movement, or fatigue for which they require ongoing management by a lymphedema therapist. CDT can include various forms of compression, exercise, skin care, and manual lymphatic drainage (MLD) massage, with compression adapted according to clinical need.[17] However, while there are published guidelines for the early detection, screening, and monitoring of breast cancer-related lymphedema in Australia,[19] there is no equivalent consensus statement for HNL.

Patients with HNL in Australia face significant barriers in accessing services because of limited availability of trained therapists and the high costs of treatment. The aim of this study was to describe the model of care and outcomes of HNL management at our institution, a high-volume center for treatment of HNC in Australia, to inform other clinicians and institutions about current management patterns and treatment outcomes. Our specific objectives were to:

1. Describe referral patterns of HNC patients with HNL for management within the service.
2. Describe the patient and treatment characteristics of those attending the service.
3. Describe the model of care, treatment approaches, and assessment tools used in routine clinical practice for HNL.

2 | MATERIALS AND METHODS

2.1 | Study design and setting

A retrospective review of all referrals for HNL to the Living Room at Chris O'Brien Lifehouse (COBLH) from January 1, 2018 to December 31, 2020 was conducted. COBLH is a comprehensive cancer center in Sydney, Australia, with a high-volume head and neck surgery service. Outpatient lymphedema assessment is offered through The Living Room, part of the Department of Integrative Oncology and Supportive Care at COBLH.

2.2 | Model of HNL care

The model of care employed by COBLH for the management of lymphedema is unique in the Australian setting in which it focuses on early intervention, rather than reactive management, and falls within a hospital department, rather than a stand-alone clinic reliant on external referrals. While hospital inpatients, surgical patients are

provided an early lymphedema management prevention plan if they are at risk of developing HNL. Referrals are accepted from within the hospital service or directly from patients who self-refer. Therapists at our institution are physiotherapists or occupational therapists who are certified in lymphedema management and registered under the Australian Health Practitioner Regulation Authority (AHPRA). After referral, initial assessments include history taking, clinical assessment, treatment planning, and instruction in self-management as well as hands-on therapy. These sessions typically last for 90 min, with follow-up appointments for progress monitoring, treatment adjustment, and patient education lasting 30–60 min. Patients are also provided with instructional videos on self-management of lymphedema as a reference for home-based therapy.

Over the study period, the HNL treatment followed a set of key principles set out by international consensus in the *Lymphedema Framework*[17]:

1. Education: Helping patients to understand lymphatic anatomy and what has changed as part of their cancer treatment.
2. Compression: Either through bandaging or compression garments.[20]
3. Skin care: Through massage, scar therapy, kinesiology taping, low-level laser therapy (with Rian Corp LTU 904[21] for 1-min intervals at various points on scar or fibrotic tissues), negative pressure therapy (with the Lymphatouch device[22]), and moisturizing with approved skin care products.
4. Exercises: Aimed at improving range of motion of the trunk, shoulders, neck, jaw, and tongue, taught through demonstration and written instruction.
5. Manual lymphatic drainage: Through massage by a therapist or self-massage, taught through demonstration (often in front of a mirror) and with written instruction.

After initial assessment, the lymphedema therapist would make a decision based on the clinical presentation as to which, and how many, modalities would be prescribed to patients, as well as accounting for each patient's goals, abilities, support network, and physical, psychosocial, and emotional capacity.

2.3 | Assessment tools

During the study period, therapists used instruments from an agreed bank of tools to objectively measure external HNL in clinical practice, aligning with practices in other institutions in Australia and the United Kingdom.[23] These included:

1. The M. D. Anderson Cancer Center (MDACC) HNL rating scale,[1,2] a 4-point scale describing the extent of HNL, ranging from Level 0 (no visible edema but patient-reported heaviness) to Level 3 (irreversible lymphedema with tissue changes).
2. The Assessment of Lymphedema of the Head and Neck (ALOHA) measurement[24] comprising three tape measurements taken on the patient's face (ear to ear, upper and lower neck circumference, and ear to mental protuberance on the left and right sides).

In addition to the above measures, clinical assessment and documentation included neck and shoulder range of motion, and qualitative indicators such as visual inspection (with photographic documentation of HNL for comparison over time) and palpation of tissue texture and pitting.

2.4 | Data collection

Electronic records at the Living Room were examined to identify patients aged ≥18 years who were referred for assessment and/or management of internal and/or external HNL during the study period. The patient's medical record was reviewed to collect patient demographic and clinical characteristics, visit numbers, referral source, cancer and lymphedema treatment history, and treatment outcomes.

2.5 | Statistical analysis

Statistical analyses were conducted using SAS Version 9.4 (Cary, NC) and $p < 0.05$ was considered statistically significant. Normality of data was assessed using the Shapiro–Wilk test and visual inspections of histograms and Q–Q plots. Continuous variables are presented as mean (standard deviation [SD]) for normally distributed data, and median (range) for nonparametric data. Categorical data are presented as counts and relative frequencies. To assess changes in objective measures of HNL from pre- to post-treatment, paired t tests were used to analyze differences in ALOHA measurement scores (continuous variables) and the Wilcoxon signed rank test to analyze changes in the MDACC rating scale scores (continuous ordinal variable).

2.6 | Ethical and regulatory approval

The study was approved by the Sydney Local Health District Human Research Ethics Committee (SLHD HREC)–

TABLE 1 Referral patterns and characteristics of the 100 patients seen by the head and neck lymphedema service from 2018 to 2020

Characteristic	Frequency (%)
Referral source to lymphedema service	
Head and neck surgeon	33 (33)
Radiation oncologist	23 (23)
Self-referral	20 (20)
Allied health professional	13 (13)
Other	11 (11)
Timing of referral	
Before treatment	5 (5)
During treatment	17 (17)
After treatment	78 (78)
Year of referral	
2018	23 (23)
2019	32 (32)
2020	45 (45)
Number of appointments per patient	Mean 3.3 (SD 4.4) Median 2 (range 1–31)
Age at referral, years	Mean 62.1 (SD 13.9) Median 61.5 (range 21–93)
Time from treatment completion to first appointment, months[a]	Mean 29.0 weeks (SD 66.4) Median 12.4 weeks (range 0.7–417 weeks)
Sex	
Male	60 (60)
Female	40 (40)
Remoteness of residence	
Metropolitan NSW	91 (91)
Regional NSW	7 (7)
Interstate	2 (2)
Primary tumor location	
Oral cavity	46 (46)
Oropharynx	34 (34)
Thyroid	7 (7)
Salivary glands	3 (3)
Nasopharynx	2 (2)
Larynx	2 (2)
Hypopharynx	1 (1)
Other	5 (5)
T-stage ($N = 6$ missing)	
Tx/T0	10 (10)
T1	22 (22)
T2	39 (29)
T3	11 (11)
T4	22 (22)
N-stage ($N = 7$ missing)	
Nx/N0	37 (37)
N1	27 (27)
N2	22 (22)
N3	7 (7)
Primary treatment	
Surgery alone	30 (30)
Surgery + radiotherapy	33 (32)
Surgery + chemoradiotherapy	17 (17)
Chemoradiotherapy	18 (18)
Radiotherapy alone	2 (2)
Chemotherapy alone	1 (1)
Surgical complexity[b] ($N = 79$)	
Complex	76 (96)
Neck dissection	21 (28)
Flap reconstruction	6 (8)
Both neck dissection and flap reconstruction	49 (65)
Noncomplex	3 (3)
Neck dissection ($N = 70$)	
Ipsilateral	56 (80)
Bilateral	14 (20)

[a]For patients referred after treatment completion ($N = 76$ with treatment dates available).
[b]Complex surgery defined as requiring neck node dissection, flap reconstruction, or both.

RPA Zone (Protocol Number: X21-0386 and 2021/ETH11920) and local site governance was approved by the Chris O'Brien Lifehouse Research Governance Office (Reference Number: LH21.066). A waiver of the requirement for consent was approved for this study.

3 | RESULTS

3.1 | Referral patterns and patient characteristics

Over the 3 year study period, a total of 100 patients were seen by the Living Room lymphedema service for an initial appointment (Table 1). The total number of appointments over the study period was 439, of which 100 were initial appointments and 339 were review appointments.

The median number of appointments attended per patient was 2 (range 1–31 appointments). The number of referrals increased from 23 in 2018, to 32 in 2019 and 45 in 2020. The majority of patients were referred by a head and neck surgeon ($N = 33$, 33%) and 20% of patients self-referred to the service. Most patients were male ($N = 60$, 60%) and the average age at presentation was 62 years (range 21–93 years). The primary tumor site was mostly in the oral cavity ($N = 46$, 46%) or oropharynx ($N = 34$, 34%), and 18 patients (18%) had recurrent disease. Most patients ($N = 80$, 80%) had surgery as part of their cancer treatment, and 70 patients (70%) underwent radiotherapy either in the primary ($N = 20$, 20%) or adjuvant setting ($N = 50$, 50%). Of the patients who underwent surgery, 78 (96%) had a complex surgery, defined as requiring either neck dissection ($N = 21$), free flap reconstruction ($N = 6$), or both neck dissection and free-flap reconstruction ($N = 49$). Of the 70 patients who underwent neck dissection, 14 patients had a bilateral and 56 patients had a unilateral neck dissection. Those who underwent a neck dissection were provided with early lymphedema management education prior to leaving hospital. The median time from treatment completion to first HNL appointment was 12.4 weeks, ranging from 0.7 to 417 weeks. Of the 100 patients who presented for initial consultation, 32 patients did not return for a follow-up appointment due to referral to another provider ($N = 8$), not recommended for further follow-up ($N = 12$), disease progression ($N = 2$), or failed to return for scheduled follow-up ($N = 10$).

3.2 | Lymphedema treatment provided

The most common form of lymphedema treatment was MLD provided by the therapist, which was prescribed to 96 (96%) patients (Table 2) and 93 patients were prescribed self-management through self-MLD. Other forms of management utilized in the clinic included HNL-specific exercises, low-level laser therapy, compression garments, kinesiology tape, and skin care. In addition to management by the lymphedema therapist, 21 patients (21%) also undertook other therapy in the Living Room in the form of acupuncture, physiotherapy for musculoskeletal issues, oncology massage focusing on the head, neck and shoulder region, and exercise physiology to assist with strength rehabilitation.

3.3 | Post-treatment changes in HNL

Of the 100 patients seen for an initial consultation, 68 (68%) returned for at least one follow-up appointment. Of these patients, 50 patients had both pre- and post-treatment ALOHA measurements taken for upper and lower neck circumference, and ear to ear length, while 33 patients had pre- and post-treatment measurements taken for ear to mental protuberance on both sides of the face (Table 3). For patients with matched data, the greatest improvement in HNL measurements were seen for upper neck circumference, with 39 (78%) patients showing (improvements mean difference [MD] −1.5 cm, $p < 0.001$). Twenty-nine patients (58%) had improvements in ear to ear length (MD −0.5 cm, $p < 0.001$). Ear to mental protuberance length improved (decreased) in 21 patients (58%) on the right side and in 20 patients (61%) on the left side (MD −0.2 cm on each side, $p = 0.004$ and $p = 0.003$, respectively). However, only seven patients (14%) had improvements in lower neck circumference where the mean difference between pre- and post-measurements was 1.4 cm ($p < 0.001$). Of the 42 patients with pre-treatment MDACC HNL scores recorded, most (63%) had Level 1a HNL (soft visible edema, no pitting). Twenty-nine patients had both pre- and post-treatment MDACC HNL scores, five of whom had an improvement (reduction) in their score. Of the remaining patients, most ($N = 18$, 62%) remained stable and six patients (21%) showed signs of worsening HNL (of which five underwent surgery with neck dissection and free flap reconstruction, followed by postoperative radiotherapy).

4 | DISCUSSION

There is increasing recognition that HNL plays an important role in the quality of life and functional outcomes of patients undergoing treatment for HNC.[25] However, to date there has been little published evidence of HNL management practices in Australia, with the majority of reports arising from institutions in the United States or United Kingdom. Retrospective evaluation of practice is critical to review potential gaps in service provision and to identify opportunities to improve access to, and patient care within the service. This is especially important given international variations in approaches to HNL, including a lack of availability of technology such as advanced pneumatic compression devices for HNL in Australia, as well as differing approaches to integrating lymphedema therapy within the multidisciplinary team. The literature concerning optimal assessment and management of HNL is rapidly growing, and this study adds to recent Australian literature evaluating institutional practices of HNL treatment and outcomes.[11,26,27] Our study reports on 100 patients who attended our HNL service over a 3-year period. Despite increasing numbers of referrals

TABLE 2 Summary of treatment provided and outcomes of patients who attended the head and neck lymphedema service from 2018 to 2020

Variables	Frequency (%)
Treatment provided	
Manual lymphatic drainage (MLD)	96 (96)
Self-management (self-MLD)	93 (93)
Lymphedema exercises	73 (73)
Low-level laser therapy (LLLT)	61 (61)
Compression garment	38 (38)
Kinesiology tape	30 (30)
Skin care	15 (15)
Other	21 (21)
Acupuncture	10 (47)
Physiotherapy	3 (10)
Oncology massage	8 (38)
Exercise physiology	6 (19)
Lymphedema assessment tools used	
ALOHA only	48 (48)
ALOHA and MDACC	35 (35)
MDACC only	4 (4)
None	10 (10)
Treatment outcomes	
Discharged—improved or self-manage	29 (29)
Lost to follow-up	36 (36)
Ongoing follow-up/treatment	12 (12)
Referred to another lymphedema therapist	16 (16)
Progressive disease	7 (7)

Abbreviations: ALOHA, Assessment of Lymphedema of the Head and Neck measurement; MDACC, The M. D. Anderson Cancer Centre HNL rating scale.

each year, overall, these figures represent relatively low rates of referral within the context of the total number patients treated for HNC at our institution each year, especially given the complex case-mix. Reasons for this relatively low referral rate could include lack of awareness among physicians about HNL (particularly internal lymphedema in the absence of external signs), availability of lymphedema therapists, costs associated with attending the service (as the service is not publicly funded), or inability to travel long distances for appointments. It is also possible that the early lymphedema management prevention plan given to surgical patients prior to returning home may protect patients from developing severe symptoms. Some 10% of patients failed to follow-up with the lymphedema service after initial assessment, and in total 36% of patients were lost to follow-up (did not return for scheduled appointments). The reasons for this could not be abstracted from medical records; however, it is possible that costs, travel burden, or even self-perceived improvement in lymphedema could have contributed to this outcome.

The treatments provided to patients in this cohort are consistent with the principles by which HNL management has been guided since international consensus was reached in 2006.[17] MLD, whether provided by the therapist or as a self-management exercise, remains the most common treatment strategy for HNL consistent with evidence supporting its effectiveness as part of complete decongestive therapy.[8] A high proportion of patients in our study (93%) were prescribed self-management. A 2020 study in Australia[28] reported on a small pilot randomized controlled trial testing the addition of a self-managed head and neck exercise regimen to usual care. The authors found that while self-management exercises for HNL are feasible from a safety and patient retention perspective, adherence to exercises (measured through daily participant diaries) remains a significant barrier. In that study, no participant reported performing head and neck exercise protocols at the minimum intensity required, and while adherence to self-lymphatic drainage was not measured, clinical observation indicated most patients were not correctly performing self-guided management. While only a small pilot study of nine patients, no reductions in extent of HNL were observed after 6 weeks of the trial for either the control or intervention groups. In the present study, we were unable to determine adherence to exercises; however, it is likely that not all patients performed home-based exercises to the required intensity. Despite this, home-based exercise programs for HNL could play a valuable role, particularly in regional and remote areas of Australia where access to therapists is limited and travel to large cities is burdensome. However as reported in the breast cancer literature,[29] adherence to self-management for breast cancer-related lymphedema is influenced by psychosocial factors, burden of treatment, insufficient education on lymphedema and exercises, and comorbidities and physiological factors such as age, arthritis, swelling, or numbness. Therefore, consideration should be given to strategies to optimize adherence to exercises (such as prescribed dose, frequency, and timing), to ensure patients have the greatest chance of successful response to therapy, and measures of compliance could be collected from patients in either research studies or as part of routine clinical care.

Approximately 20% of patients in this cohort undertook complementary therapies, with acupuncture and

TABLE 3 Assessment of Lymphedema of the Head and Neck measurement (ALOHA) and The M. D. Anderson Cancer Centre HNL (MDACC HNL) rating scale scores of patients who attended the head and neck lymphedema service, including changes in scores for patients with data available both pre- and post-treatment

Outcome	Pre-treatment measurement		Post-treatment measurement		Mean difference[a]		
ALOHA measurement	***N***	**Mean score (SD)**	***N***	**Mean score (SD)**	***N***	**Mean score (SD)**	***p*-value[b]**
Upper neck circumference (cm)	86	41.3 (5.8)	50	41.1 (6.0)	50	−1.5 (1.9)	<0.001
Lower neck circumference (cm)	87	40.8 (5.4)	51	40.6 (5.8)	50	1.4 (1.8)	<0.001
Ear to ear length (cm)	87	25.8 (2.7)	51	25.8 (2.7)	50	−0.5 (1.1)	0.004
Ear to mental protuberance, right (cm)	62	14.2 (1.2)	34	14.2 (1.2)	33	−0.2 (0.4)	0.003
Ear to mental protuberance, left (cm)	62	14.2 (1.1)	34	14.2 (1.2)	33	−0.2 (0.3)	<0.001

	Pre-treatment measurement		Post-treatment measurement		Change after treatment		
MDACC	***N***	**%**	***N***	**%**	**Change**	***N* (%)**	***p*-value[c]**
0 (no visible edema, patient reports heaviness)			1	3	Improved	5 (17)	
1a (soft, visible edema; no pitting, reversible)	26	62	17	59	Stable	18 (62)	
1b (soft pitting edema; reversible)	11	26	6	21			
2 (firm pitting edema, not reversible, no tissue changes)	5	12	5	17	Worsened	6 (21)	1.00
3 (irreversible, tissue changes)							
Total	42	100	29	100		29 (100)	

Abbreviations: ALOHA, Assessment of Lymphedema of the Head and Neck measurement; MDACC, The M. D. Anderson Cancer Centre HNL rating scale.
[a]For patients with pre- and post-treatment scores only.
[b]Paired *t* test.
[c]Wilcoxon signed-rank test.

oncology massage being the most common. This reflects the nature of the service under which lymphedema therapy is offered in our institution, which promotes an integrative model of care for cancer survivors. All were also seen by a physiotherapist prior to leaving hospital, a dietitian to support their nutrition, and a speech pathologist for management of trismus, speech, and swallowing problems arising from their treatment. This is an area of where greater collaboration may be of benefit given the expected under-representation of internal lymphedema via current referral pathways but known significant impact that internal lymphedema could have on swallowing,[30] voicing and speech. Indeed, a recent case series has demonstrated that MLD can improve swallowing outcomes.[31] This may offer an opportunity for a collaborative approach between lymphedema therapists and speech pathologists when addressing the often severe functional impacts that HNC treatment can have on swallowing and speech.

The objective measurement tools most frequently used were the ALOHA measurement and the MDACC HNL rating scale, consistent with other Australian institutions.[11,26] While these tools were not used consistently across the service, in the 50 patients where these measures were taken before and after, there were significant improvements in the degree of lower and upper neck lymphedema, and ear to ear lymphedema, though not ear to mental protuberance measures. These findings are similar to those in a 2017 Australian study[26] that reported significant improvements in the same measures (upper and lower neck, and ear to ear edema) following a 22-week intervention involving both therapist-led and participant self-HNL management. However, in our study, we observed six patients in our study whose MDACC level worsened after treatment, in comparison to the results from Piggott and colleagues where 8 of the 10 participants improved, with two remaining stable. Due to the small cohorts in both studies, it is difficult to draw conclusions on why this may have occurred based on the characteristics of the patients. However, in our study, five of the six patients whose MDACC scores worsened underwent radical surgery involving both neck dissection and free flap reconstruction, followed by postoperative radiotherapy. Further, all were referred either during radiotherapy or within 3 months of treatment, so it is possible that the ongoing effects of treatment, continued development of lymphedema, and diminished capacity to adhere to MLD during radiation were contributing factors. Future studies may therefore be warranted in which outcomes are assessed for different subsets of

patients depending upon cancer treatment received (surgery, radiotherapy, or combination), as well as to determine the optimal timing for commencement of lymphedema therapy in the post-treatment phase. In addition, the differences may also be due to different study designs, with our study a retrospective assessment of usual practice, in contrast to the prospective study by Piggott in which adherence to the intervention and follow-up schedule was more controlled.

Since the end of the study period, several changes have been made within our institution's lymphedema service. There has been increased demand for the HNL service resulting from an increased awareness of HNL itself and the role of service by other members of the multidisciplinary clinical team, which has necessitated additional specialist training for therapists to meet this demand. The LymphScanner (Delfin Technologies, Kuopio, Finland)[32] has been increasingly used as a noninvasive tool to measure localized and chronic lymphedema. The LymphScanner uses magnetic waves to measure subcutaneous fluid at a depth of 2.5 mm, providing a reading of percent water content (PWC) in tissues. The device facilitates rapid objective assessment of PWC, allowing the therapist to localize and map the extent of lymphedema, which can be used to plan treatment interventions and monitor change over time. Online education has also been enhanced in order to reach patients who may have limited access to HNL services, either because of distance to or limited availability of services, or the COVID-19 pandemic which limited face-to-face consultations, which has been facilitated by ongoing collaboration with inpatient/ward-based physiotherapy teams. Short videos co-developed by lymphedema therapists and speech pathologists are also available for patients, providing guidance on common side effects of HNC treatment (lymphedema and trismus), self-management of HNL using MLD, and scar massage, and are now part of standard practice as a coaching tool at our institution. Monthly lymphedema education sessions are also provided by the service, provided in-person and via videoconferencing, providing information on lymphedema and the principles of early intervention. Some 20% of patients in this cohort self-referred to the clinic, potentially in response to the increased focus on education about HNL increasing patient awareness of the service.

To our knowledge, this is the first single-institution retrospective study evaluating the HNL service at a comprehensive cancer center in Australia. One strength of this study is the collection of data from consecutive patients referred to the service over the specified study period. However, given the absence of standardized referral pathways both within our institution and the Australian health system more broadly, it is likely that the study cohort is subject to selection bias and may not represent all patients with HNC at risk of HNL, nor those who developed HNL. We collected a broad range of patient and clinical data, including the use of objective measurement tools and adjunctive treatment for HNL, which further characterizes our study population. However, as data were collected from administrative health databases and not a purpose-built research database, we were unable to collect all outcomes and variables relevant to our cohort, nor were we able to include a control group who did not undergo lymphedema treatment for comparison of outcomes. Additionally, this is a single-center study, which limits the generalizability to other institutions and countries. Our institution is a quaternary referral high-volume center often managing cases requiring multimodality therapies and complex surgical approaches, which takes patients statewide from both metropolitan and regional areas, which are likely to lead to the development of HNL. Despite the high-volume of patients treated at our institution, we observed a relatively low rate of referral to and uptake of HNL services (an average of 33 patients per year), which may reflect lack of awareness about HNL itself or services to address it, or other barriers previously mentioned such as availability of therapists or costs of treatment. This retrospective study has therefore identified an important question to be explored in future evaluations of the service regarding awareness and referral practices. In addition, we were unable to collect data on reasons why patients were not referred to the lymphedema service owing to the retrospective nature of this study, or the reasons why some patients disengaged from the lymphedema service, as we relied on data from medical records that were not documented with research as the intent. Finally, the data primarily represents the outcomes from those being treated for external lymphedema rather than internal, given evidence suggesting that the largest proportion of patients with lymphedema have both internal and external,[33] it is possible that internal lymphedema was missed and perhaps incompletely managed. This is concerning as Jeans and colleagues have shown that patients are more likely to develop severe dysphagia.[6] These data could be the focus of a prospective study, to provide insight into the experiences and barriers faced by clinicians and patients in accessing HNL services.

Currently, there are no standard referral guidelines for HNL within our institution, nor are there consensus guidelines in Australia or internationally. Development of a standard clinical care pathway and treatment protocol, which could encourage early detection and potential referral prior to completion of cancer treatment, may help to avoid potential delays in accessing services in resource-limited settings and improve provision of the right

treatment at the right time. Patients who are scheduled to undergo surgery and/or radiotherapy for HNC could be identified or flagged by the multidisciplinary team early and be placed on a treatment pathway to include early monitoring for both internal and external HNL. Appropriate referrals to experienced clinicians, either within the institution or at other sites could be made early to maximize chances of a good recovery. Lastly, management of HNL and treatment protocols could also be guided by recent advances in imaging of drainage routes of the head and neck lymphatic system, as seen through use of indocyanine green fluorescence (ICG) lymphography in patients breast cancer lymphedema.[34] Knowledge of an individual's unique lymphatic drainage patterns can be used to guide the practice of MLD and provide highly personalized therapy. Preliminary studies from the United States have also shown promising results for the use of pneumatic compression for HNL using the Flexitouch system (Tactile Medical, Minneapolis, MN), with several studies demonstrating high levels of compliance, satisfaction, and feasibility,[35–37] as well as efficacy in improving functional, aesthetic, and symptom-related outcomes.[35–38] Larger trials are currently underway to determine efficacy of advanced pneumatic compression compared to CDT; however, pneumatic compression devices for HNL are yet to be made available in Australia. Lastly, there is an ongoing campaign by the Australasian Lymphology Association (ALA) seeking to have lymphedema therapy included on the Australian Medicare Benefits Schedule (MBS), a listing of health services subsidized by the Australian Government. Addition of lymphedema therapy to the MBS is expected to improve accessibility of the service to a greater proportion of people living with lymphedema, including those who do not access treatment due to financial barriers, and may improve awareness, accuracy, and timeliness of diagnosis of lymphedema.

5 | CONCLUSION

Patients treated for HNC, especially those who undergo multimodality therapy, experience high prevalence of HNL. This retrospective review suggests that HNL can be managed in the outpatient setting through a combination of therapist led and self-MLD, massage, and other exercises. However, prospective controlled studies are needed to evaluate the optimal timing and dose of HNL therapy, as adherence to exercises, especially self-MLD, can vary greatly between patients. Initiatives to screen for internal and external lymphedema could be considered as early in the treatment pathway as possible, to ensure patients at risk of developing HNL have access to effective therapies before irreversible tissue changes develop and key functions such as swallowing are compromised.

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DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available from the corresponding author upon reasonable request.

ETHICS STATEMENT

The study was approved by the Sydney Local Health District Human Research Ethics Committee (SLHD HREC)–RPA Zone (Protocol Number: X21-0386 and 2021/ETH11920) and local site governance was approved by the Chris O'Brien Lifehouse Research Governance Office (Reference Number: LH21.066). A waiver of the requirement for consent was approved for this study.

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REFERENCES

1. Executive Committee. The diagnosis and treatment of peripheral lymphedema: 2016 consensus document of the international society of lymphology. *Lymphology*. 2016;49:170-184.
2. Smith BG, Lewin JS. Lymphedema management in head and neck cancer. *Curr Opin Otolaryngol Head Neck Surg*. 2010;18:153-158.
3. Murphy BA, Deng J. Advances in supportive care for late effects of head and neck cancer. *J Clin Oncol*. 2015;33:3314-3321.
4. Ringash J. Survivorship and quality of life in head and neck cancer. *J Clin Oncol*. 2015;33:3322-3327.
5. Ridner SH, Dietrich MS, Niermann K, Cmelak A, Mannion K, Murphy B. A prospective study of the lymphedema and fibrosis continuum in patients with head and neck cancer. *Lymphat Res Biol*. 2016;14:198-205.
6. Jeans C, Ward EC, Brown B, et al. Association between external and internal lymphedema and chronic dysphagia following head and neck cancer treatment. *Head Neck*. 2021;43:255-267.
7. Jeans C, Ward EC, Cartmill B, et al. Patient perceptions of living with head and neck lymphoedema and the impacts to swallowing, voice and speech function. *Eur J Cancer Care (Engl)*. 2019;28:e12894.
8. Smith BG, Hutcheson KA, Little LG, et al. Lymphedema outcomes in patients with head and neck cancer. *Otolaryngol Head Neck Surg*. 2015;152:284-291.
9. Doersam JK, Dietrich MS, Adair MA, Rhoten B, Deng J, Ridner SH. A comparison of symptoms among patients with

head and neck or truncal lymphedema and normal controls. *Lymphat Res Biol*. 2019;17:661-670.
10. Deng J, Sinard RJ, Murphy B. Patient experience of head and neck lymphedema therapy: a qualitative study. *Support Care Cancer*. 2019;27:1811-1823.
11. Jeans C, Brown B, Ward EC, et al. Comparing the prevalence, location, and severity of head and neck lymphedema after post-operative radiotherapy for oral cavity cancers and definitive chemoradiotherapy for oropharyngeal, laryngeal, and hypo-pharyngeal cancers. *Head Neck*. 2020;42:3364-3374.
12. Melissant HC, Jansen F, Eerenstein SE, et al. Body image distress in head and neck cancer patients: What are we looking at? *Support Care Cancer*. 2021;29:2161-2169.
13. Dahill A, Al-Nakishbandi H, Cunningham KB, Humphris GM, Lowe D, Rogers SN. Loneliness and quality of life after head and neck cancer. *Br J Oral Maxillofac Surg*. 2020;58:959-965.
14. North AS, Carson L, Sharp L, Patterson J, Hamilton DW. The unmet needs of patients with advanced incurable head and neck cancer and their carers: a systematic review and meta-ethnography of qualitative data. *Eur J Cancer Care*. 2021;30: e13474.
15. Deng J, Ridner SH, Dietrich MS, et al. Prevalence of secondary lymphedema in patients with head and neck cancer. *J Pain Symptom Manage*. 2012;43:244-252.
16. McGarvey AC, Osmotherly PG, Hoffman GR, Chiarelli PE. Lymphoedema following treatment for head and neck cancer: impact on patients, and beliefs of health professionals. *Eur J Cancer Care (Engl)*. 2014;23:317-327.
17. Lymphoedema Framework. *Best Practice for the Management of Lymphoedema. International Consensus*. MEP Ltd; 2006.
18. Deng J, Ridner SH, Murphy BA. Lymphedema in patients with head and neck cancer. *Oncol Nurs Forum*. 2011;38:E1-E10.
19. Australasian Lymphology Association. *Position Paper: Early Detection of Breast Cancer-Related Lymphoedema*. ALA; 2019.
20. Australasian Lymphology Association. *Position Paper: The Use of Compression in the Management of Lymphoedema*. ALA; 2019.
21. RianCorp. Low level laser therapy (LLLT); 2022.
22. LymphaTouch. LymphaTouch Product LT01; 2022.
23. Purcell A. Head and neck lymphoedema management practices. *J Lymphoedema*. 2013;8:8-15.
24. Purcell A, Nixon J, Fleming J, McCann A, Porceddu S. Measuring head and neck lymphedema: the "ALOHA" trial. *Head Neck*. 2016;38:79-84.
25. NSW Agency for Clinical Innovation. *Lymphoedema: A Guide for Clinical Services*. ACI; 2018.
26. Pigott A, Nixon J, Fleming J, Porceddu S. Head and neck lymphedema management: evaluation of a therapy program. *Head Neck*. 2018;40:1131-1137.
27. Pigott A, Brown B, Trevethan M, et al. Head and neck lymphoedema-research challenges during the COVID-19 pandemic. *Br J Community Nurs*. 2021;26:S6-S15.
28. McLaughlin TM, Broadhurst JJ, Harris CJ, McGarry S, Keesing SL. A randomized pilot study on self-management in head and neck lymphedema. *Laryngosc Invest Otolaryngol*. 2020;5:879-889.
29. Ostby PL, Armer JM. Complexities of adherence and post-cancer lymphedema management. *J Pers Med*. 2015;5:370-388.
30. Jackson LK, Ridner SH, Deng J, et al. Internal lymphedema correlates with subjective and objective measures of dysphagia in Head and neck cancer patients. *J Palliat Med*. 2016;19:949-956.
31. Deng J, Murphy B, Dietrich MS, Bartow C, Adcock D, Moore A. *Effects of Manual Lymph Drainage on Lymphoedema and Dysphagia in Head and Neck Cancer: A Case Series*. Wounds International; 2019:22-26.
32. Delfin Technologies. LymphScanner; 2022.
33. American Head & Neck Society. *Lymphedema*. AHNS; 2022.
34. Suami H, Heydon-White A, Mackie H, Czerniec S, Koelmeyer L, Boyages J. A new indocyanine green fluorescence lymphography protocol for identification of the lymphatic drainage pathway for patients with breast cancer-related lymphoedema. *BMC Cancer*. 2019;19:985.
35. Gutiérrez C, Mayrovitz HN, Naqvi SHS, Karni RJ. Longitudinal effects of a novel advanced pneumatic compression device on patient-reported outcomes in the management of cancer-related head and neck lymphedema: a preliminary report. *Head Neck*. 2020;42:1791-1799.
36. Mayrovitz HN, Ryan S, Hartman JM. Usability of advanced pneumatic compression to treat cancer-related head and neck lymphedema: a feasibility study. *Head Neck*. 2018;40:137-143.
37. Ridner SH, Dietrich MS, Deng J, Ettema SL, Murphy B. Advanced pneumatic compression for treatment of lymphedema of the head and neck: a randomized wait-list controlled trial. *Support Care Cancer*. 2021;29:795-803.
38. Gutierrez C, Karni RJ, Naqvi S, et al. Head and neck lymphedema: treatment response to single and multiple sessions of advanced pneumatic compression therapy. *Otolaryngol Head Neck Surg*. 2019;160:622-626.

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