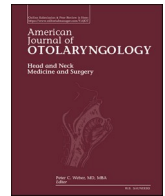




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## Feasibility and efficacy of home-based lymphedema exercises for head and neck cancer patients at a safety net hospital

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### ABSTRACT

**Purpose:** Lymphedema therapy is an effective tool in mitigating head and neck lymphedema morbidity and long-term fibrosis. Studies have shown the efficacy of facility-based therapy; however, access can be limited by sociodemographic factors, including socioeconomic status and transportation. This study evaluates the feasibility and effectiveness of home-based lymphedema therapy in a socially vulnerable patient population.

**Materials and methods:** A retrospective chart review analyzed patients who underwent home-based lymphedema exercise regimen after training with a lymphedema-trained speech language pathologist between 2019 and 2022 at a tertiary academic medical center. Patient and cancer demographics were collected. Primary outcomes measured were quality of life surveys and diet status.

**Results:** Of the 27 patients included, 85.1 % were in the two highest quintiles of neighborhood deprivation based on national Area Deprivation Index (ADI). Treatment breakdown included 78 % who were treated with surgery, 96 % completed radiation and 59.3 % chemotherapy. Six months after initiating lymphedema therapy, most patients (59.3 %) were compliant with exercises. Quality of life scores showed trends toward improvement, but only a decrease in condition-related anxiety at 3 months ( $p = 0.004$ ) reached statistical significance. Improvement in diet was significant at 6 and 9 months after initiation of treatment ( $p = 0.020$ ).

**Conclusions:** Patient compliance rate demonstrates feasibility of home exercises for lymphedema treatment in a tertiary care setting with a socially vulnerable patient population. Home-based head and neck lymphedema treatment showed improvements in patient diet over time.

### 1. Introduction

Head and neck lymphedema (HNL) is a common side effect of head and neck cancer (HNC) treatment, with a reported incidence ranging from 12 % to 98 % of HNC survivors [1]. Derangement in lymphatic structures and surrounding soft tissue may be caused by direct removal or damage during surgery or radiotherapy, as well as post-operative scarring and radiation-induced fibrosis. In the head and neck, lymphedema can form externally in the soft tissues of the face and neck as well as internally in the oral cavity, pharynx, and larynx [1,2]. HNL has been proven to result in decreased quality of life with debilitating physical, functional, and psychological symptoms for HNC survivors [1,2]. It can cause decreased range of motion in the neck, musculoskeletal pain,

difficulty swallowing, altered speech and impaired vocalization, and airway compromise [1–3]. In addition, patients report numerous psychological symptoms including frustration, embarrassment, and depression due to both functional and cosmetic changes [3]. Body image distress has been reported in 13–20 % of patients resulting in social withdrawal and disengagement [1].

Complete decongestive therapy (CDT) is the gold standard for lymphedema therapy in the extremities and is commonly employed in the head and neck [4,5]. CDT is a multimodal treatment which combines manual lymphatic drainage (MLD) massage with compression dressings, skin care, and simple physical exercise. The goals of CDT are to decongest the soft tissues, prevent refilling, and promote improved drainage thereby reducing swelling, improving skin condition, and increasing

**Abbreviations:** HNL, head and neck lymphedema; HNC, head and neck cancer; CDT, complete decongestive therapy; MLD, manual lymphatic drainage; ADI, area deprivation index; UW-QOL, University of Washington Quality of Life Questionnaire; FHNSI, Functional Assessment of Cancer Therapy Head and Neck Cancer Symptom Index; SLP, Speech and Language Pathology.

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mobility of the soft tissues. Traditionally, CDT has involved an initial intensive phase of outpatient treatment with a certified lymphedema therapist several times each week for approximately 4 weeks. This is then followed by a maintenance phase of less frequent visits and daily home treatment performed by the patient or caretaker [1–3].

Studies assessing head and neck lymphedema therapy have shown greater efficacy of facility-based therapy; however, access can be limited due to patient socioeconomic status and transportation access [7,8]. In a study interviewing HNC patients in rural communities, access was cited as a significant barrier to care, and patients were highly reliant on caregivers for transportation [9]. Therapists who offer head and neck lymphedema therapy are often found at tertiary care centers where head and neck cancer is more commonly treated. The transportation costs coupled with additional time away from work for patients and caregivers create significant barriers to regular therapy visits for patients in socially vulnerable populations.

Our study aimed to provide a home-based HNL therapy program to patients at a tertiary safety-net hospital to evaluate feasibility of patient compliance and assess the impact on patient-reported quality of life and diet. We hypothesized that a home-based therapy program would be feasible for treatment in a heavily socioeconomically disadvantaged patient population in a predominantly rural setting and would lead to improvements in quality of life scores and diet.

## 2. Materials and methods

Approval for this study was obtained from the University of Mississippi Institutional Review Board (UMMC-IRB-2023-79). Retrospective chart review was performed of patients who underwent home-based lymphedema exercise therapy between 2019 and 2022 at a tertiary safety net hospital. The study included participants >18 years of age, who exhibited clinical signs of lymphedema after receiving head and neck cancer treatment. Patients were required to have imaging that demonstrated no evidence of disease prior to initiation of lymphedema therapy. Patients were evaluated by a lymphedema-trained speech-language pathologist who performed a lymphedema consultation and provided education on the home-based exercise therapy tailored specifically for head and neck lymphedema patients. Patients were also given an informative handout detailing the steps of the therapy to reinforce this technique.

A comprehensive chart review was conducted using the patients' electronic medical records. The investigators collected demographic information such as age, sex, and race. Area deprivation index (ADI), a neighborhood level ranking of socioeconomic disadvantage, was recorded at both the state and national level [10]. Data was collected on cancer-related characteristics, including subsite, pathology, TNM staging, and specific cancer treatments received were documented. Data on patient compliance with exercises was collected through patient reported outcomes. Diet was collected at baseline and at 3-month intervals and was categorized as regular, soft, liquids, or PEG dependent. Quality of life scores were measured at baseline and at 3-month intervals using the University of Washington Quality of Life Questionnaire (UW-QOL) and the Functional Assessment of Cancer Therapy Head and Neck Cancer Symptom Index (FHNSI) [11,12]. The UW-QOL evaluates physical function and social-emotional function specifically for HNC patients. FHNSI is an additional 10 question survey of physical and functional well-being in HNC patients. Each survey was scored using a unique system before analysis [11–13].

### 2.1. Statistical analysis

Primary statistics were described using frequencies and percentages for categorical variables and mean and standard deviations for continuous variables. For the analysis to determine any increase in means of UWQOL and FHNSI over time, and its significance, descriptive analysis and Friedman's analysis were conducted, respectively. As the data were

not normally distributed, non-parametric tests, including the Friedman test, Wilcoxon signed-rank test, and Kruskal-Wallis test, were employed. Chi-square analysis and correlation analysis were also conducted to explore the relationship between diet and type and extent of surgery. Statistical analysis and data management were performed using IBM SPSS v28, with the *p*-value set at <0.05.

## 3. Results

### 3.1. Patient characteristics

This study cohort included 27 patients with an average age of 62 years old. Among them, 74.1 % were male ( $n = 20$ ), and 25.9 % were female ( $n = 7$ ). Regarding race/ethnicity, 66.7 % of patients were Non-Hispanic White ( $n = 18$ ), and 33.3 % were Non-Hispanic Black ( $n = 9$ ). ADI was divided into quintiles for analysis with lowest quintiles (ADI, 0–20 %) representing the most affluent areas and highest quintile (ADI, 81–100 %) representing the most deprived areas. Most patients (85.1 %) fell into the 4th and 5th quintiles, specifically, 44.4 % in the 4th quintile ( $n = 12$ ), and 40.7 % in the 5th quintile ( $n = 11$ ).

The most common cancer subsites were base of tongue ( $n = 5$ ), supraglottis ( $n = 5$ ), and tonsil ( $n = 5$ ), each accounting for 18.5 % of cases. Oropharyngeal cancer overall accounted for 37 % of patients ( $n = 10$ ), all of which tested positive for the p16 tumor suppressor protein. Among the patients, 74 % were diagnosed with advanced stage cancer (stage III/IV) ( $n = 20$ ). For cancer treatment, 77.8 % underwent surgery ( $n = 21$ ), with 29.6 % of patients having bilateral neck dissection ( $n = 8$ ) and 37 % having a unilateral neck dissection ( $n = 10$ ). Nine patients had no neck dissection. Additionally, all but one patient received radiation therapy (96.3 %,  $n = 26$ ), and 59.3 % were treated with chemotherapy ( $n = 16$ ). All patients had at least 9 months of follow up. Following treatment initiation, 77.8 % of patients continued with lymphedema exercises at 3 months ( $n = 21$ ), 59.3 % at 6 months ( $n = 16$ ), and 44.4 % ( $n = 12$ ) at 9 months. Patient demographics can be viewed in [Table 1](#).

### 3.2. Quality of life assessment

Quality of life surveys were collected during patient surveillance visits and were available for analysis. When comparing mean quality of life scores prior to initiation of lymphedema treatment, no variations were found among ADI quintiles. [Table 2](#) demonstrates mean quality of life scores over the 9-month period after initiating lymphedema treatment. There was a trend toward improvement in questions related to pain, appearance, breathing, swallowing, and chewing; however, only the question assessing condition related anxiety showed statistically significant improvement ( $p = 0.004$ ). There were no significant differences in quality-of-life scores when stratified by type of surgery.

### 3.3. Impact on diet

A Wilcoxon Signed rank test was conducted to evaluate if there was any significant difference in diet over time after initiation of therapy. Diet status was obtained for 25 patients pre-treatment, 21 patients at 3-months, 15 patients at 6-months, and 12 patients at 9-months.

When evaluating the cohort, there was no statistically significant improvement in diet status at 3 months (Pre-treatment vs Diet 3 months:  $p = 0.279$ ); however, at 6 months of treatment, a measurable improvement in diet habits emerged (Pre-treatment vs Diet 6 months:  $p = 0.02$ ) and persisted at 9 months (Pre-treatment vs Diet 9 months:  $p = 0.02$ ). All 12 patients for whom data was able to be collected at 9-months reported a regular diet. The complete data set of diet groups over time can be found in [Table 3](#).

When diet groups were stratified by type of surgical operation (laryngectomy, glossectomy, TORS), there were no statistically significant differences in patient diets. When stratified by neck dissection status (no neck dissection, unilateral, bilateral), a statistically significant (3

**Table 1**  
Demographics.

Variables	Mean (S.D) or frequency (%)
Age	61.59 (8.859)
Gender	
Male	20 (74.1 %)
Female	7 (25.9 %)
Race	
Non-Hispanic White	18 (66.7 %)
Non-Hispanic Black	9 (33.3 %)
ADI National Groups	
0–20	0 (0 %)
21–40	2 (7.4 %)
41–60	2 (7.4 %)
61–80	12 (44.4 %)
81+	11 (40.7 %)
Cancer subsite	
Larynx	6 (22.2 %)
Hypopharynx	1 (3.7 %)
Nasopharynx	1 (3.7 %)
Oral cavity	5 (18.5 %)
Oropharynx	10 (37 %)
Thyroid	1 (3.7 %)
Parotid	1 (3.7 %)
Unknown primary	2 (7.4 %)
P16+	10 (37 %)
Overall cancer stage	
I	4 (14.8 %)
II	3 (11.1 %)
III	8 (29.6 %)
IV	12 (44.4 %)
Treatment with surgery	21 (77.8 %)
Laryngectomy	4 (14.8 %)
Glossectomy	8 (29.6 %)
Mandibulectomy	1 (3.7 %)
Transoral Robotic Surgery (TORS)	4 (14.8 %)
Neck dissection	
Unilateral	10 (37 %)
Bilateral	8 (29.6 %)
None	9 (33.3 %)
Radiation treatment	26 (96.3 %)
Chemotherapy treatment	16 (59.3 %)

months:  $p = 0.029$ ; 6 months:  $p = 0.042$ ) difference in diet was seen with extent of surgical procedure. However, when following diet outcomes of unilateral and bilateral neck dissection groups individually, at 3 months (Pre-treatment vs Diet 3 months: unilateral— $z = -1.342$ ,  $p$  value = 0.180; bilateral— $z = -1.000$ ,  $p$  value = 0.317), 6 months (unilateral— $z = -1.342$ ,  $p$  value = 0.180; bilateral— $z = -1.414$ ,  $p$  value = 0.157), and 9 months (unilateral— $z = -1.342$ ,  $p$  value = 0.180; bilateral— $z = -1.414$ ,  $p$  value = 0.157) the relation was insignificant. No relationship was observed between a history of chemotherapy or radiation therapy and changes in diet over time.

**4. Discussion**

Our study has shown that home-based HNL therapy is feasible in a socially vulnerable population, with relatively high compliance rates (59.3 % at 6 months). It has been shown in prior literature that head and neck cancer survivors with a higher degree of lymphedema have increasing symptom burden and lower quality of life [14]. Patients with increasingly severe HNL have been shown to have more significant swallowing dysfunction and dietary modifications [15]. We chose to use quality-of-life measurements and diet status as our outcome measures given our overall goal of utilizing the program to improve patient-reported symptom burden. Additionally, there can be difficulty obtaining objective measurements in a population that has limitations in healthcare access. While we hypothesized that patient engagement in home-based lymphedema treatment could improve quality of life scores, we did not find any statistically significant improvements other than in

**Table 3**  
Frequency in diet groups over time.

Diet group	Pre n = 25	3 months n = 21	6 months n = 15	9 months n = 12
Regular	13 (48.1 %)	14 (51.9 %)	13 (48.1 %)	12 (44.4 %)
Soft	11 (40.7 %)	6 (22.2 %)	2 (7.4 %)	–
Liquids	1 (3.7 %)	–	–	–
PEG	–	1 (3.7 %)	–	–

**Table 2**  
Means of UW QOL and FHNSI.

UW QOL	Pre (n = 23)	3 months (n = 21)	6 months (n = 16)	9 months (n = 12)	p-Value
Q1-pain	67.39 (34.898)	76.19 (24.336)	79.69 (24.527)	81.25 (21.651)	0.701
Q2-appearance	65.26 (25.712)	71.43 (26.559)	78.13 (23.936)	77.08 (19.824)	0.519
Q3-activity	65.30 (25.599)	72.62 (23.591)	71.87 (25.617)	81.25 (24.133)	0.392
Q4-recreation	71.78 (26.318)	77.38 (22.227)	76.56 (21.348)	79.17 (23.436)	0.719
Q5-swallowing	73.96 (29.388)	78.10 (18.061)	80.63 (20.156)	80 (14.771)	0.392
Q6-chewing	71.74 (33.119)	78.57 (25.355)	80 (31.623)	86.36 (23.355)	0.223
Q7-speech	78.88 (35.196)	72.63 (34.131)	84.29 (21.381)	73.13 (32.835)	0.392
Q8-shoulder	78.33 (30.534)	87.89 (23.233)	86.43 (21.342)	88.75 (15.526)	1.000
Q9-taste	55.11 (31.654)	53.68 (27.530)	66.43 (30.786)	76.25 (23.867)	0.801
Q10-saliva	60.67 (37.461)	56.32 (29.1)	74.29 (27.656)	76.25 (23.867)	0.463
Q11-mood	73.67 (26.228)	71.05 (23.955)	82.14 (20.636)	78.13 (24.8)	0.392
Q12-anxiety	75.06 (29.407)	74.74 (32.552)	75.71 (26.228)	83.15 (25.6)	0.572

FHNSI	Pre (n = 22)	3 months (n = 19)	6 months (n = 16)	9 months (n = 12)	p-Value
Q1-pain	1.23 (1.270)	1.06 (1.211)	0.69 (0.793)	0.92 (1.165)	0.745
Q2-energy	1.27 (1.316)	1.42 (1.121)	1.06 (1.124)	0.83 (1.193)	0.908
Q3-swallow	1.86 (1.316)	2.28 (1.274)	2.50 (1.506)	2.67 (1.073)	0.861
Q4-pain	1.41 (1.436)	1 (1.155)	0.87 (0.915)	0.83 (0.937)	0.298
Q5-breathing	0.73 (0.935)	0.58 (1.071)	0.37 (0.619)	0.08 (0.289)	0.147
Q6-communicate	2.76 (1.640)	3 (1.414)	2.81 (1.721)	3 (1.537)	0.504
Q7-nausea	0.68 (1.211)	0.47 (0.905)	0.56 (1.263)	0.50 (1.00)	0.468
Q8-solid foods	2.81 (1.401)	2.58 (1.465)	2.75 (1.528)	3.42 (0.669)	0.767
Q9-condition related anxiety	1.50 (1.263)	0.79 (1.032)	0.75 (1.065)	0.75 (0.866)	0.004
Q10-quality of life	2.27 (1.420)	2.74 (1.284)	2.75 (1.390)	3.17 (1.193)	0.575

improvement in condition related anxiety over time ( $p = 0.004$ ). This could be limited by our small sample size. To our knowledge, this is one of few studies evaluating impact of lymphedema treatment utilizing validated quality of life surveys.

Jansen et al. conducted a randomized control trial with a self-help exercise program in laryngectomy patients that included flexibility, range of motion, and lymphedema exercises. Patients in the intervention group reported improvements in swallowing and communication problems over time compared to controls. There were however no significant improvements found relating to speech, shoulder problems or health related quality of life, and overall cost utility was not uniformly beneficial between the control and intervention groups [6]. Deng et al. recently published their validated Head and Neck Lymphedema and Fibrosis Symptom Inventory which was validated in a group of oropharynx and oral cavity cancer patients. This 33-item questionnaire was developed to capture lymphedema and fibrosis symptom burden and functional impairments [16]. With further validation, this questionnaire has the potential to improve reporting of patient outcomes of lymphedema treatment.

While prior studies have shown improved efficacy in facility-based treatment programs, efficacy of home-based therapies have shown promise in the ability to impact patient quality of life particularly in groups where patient compliance with exercise regimen was high [6]. Smith and Lewis published their outpatient lymphedema treatment model from MD Anderson Cancer Center which includes an aggressive home-based treatment regimen performed by the patient or caregiver. They have found that patients with HNL benefit from self-administered treatment in the home setting, with this type of program being especially suitable for patients who cannot participate in prolonged periods of outpatient treatment due to financial, geographic or transportation restrictions [4]. Ozdemir et al. performed a prospective randomized control trial of 21 patients, evaluating the effects of CDT and home programs on external head and neck lymphedema. This study used objective facial and neck measurements but no patient-reported outcomes. They showed objective improvements in some measurement areas for both in office and home program compared to the control group, however, they reported marginally better outcomes for the in-office therapy program [8]. Despite their findings, this study showed viability for home-based therapy in certain patient populations in which 5 days per week therapy visits would not be feasible given the barriers to access and additional costs.

While facility-based therapy utilizing CDT has shown greater efficacy in treatment of HNL, access can be limited due to patient socioeconomic status and transportation access [7,8]. Douthin et al. showed in a 2015 study that rural patients are less likely to seek health care due to a number of disparities when compared to urban populations. Some barriers cited in this study included financial constraints, lack of providers in the area and scarcity of services, and insufficient public transportation [17]. In a study conducted at a high-volume comprehensive cancer center based in Sydney, Australia, 100 patients were enrolled in a head and neck lymphedema program with focus on early intervention and at home therapy due to the limited access in Australia to trained therapists as well as high costs of therapy visits. Following the initial visit, 68 % of patients returned for at least one follow up appointment and a majority showed at least some improvement in objective measurements. No patient-reported outcomes were collected in this study [1]. This study demonstrated feasibility of home-based therapy for patients in a population like our own, in which there are significant barriers to health care access and lymphedema specialists.

Our study adds to previous literature showing that home-based HNL therapy is a viable option. We have demonstrated feasibility as a relatively high rate of continued exercise participation can be achieved in populations with limitations regarding healthcare access and other social drivers of health at a safety net facility. Our protocol employs the use of a self-guided home-based therapy education training at the first visit with a speech and language pathologist (SLP), and only requires

follow up every three months. Our idea for implementation of a home-based HNL therapy program was born out of need to serve the patient population captured by our tertiary safety net hospital. Our study population has a high degree of disparity, with 85 % of our patients falling within the 4th and 5th ADI quintiles which have the highest levels of neighborhood deprivation. Higher levels of neighborhood deprivation have been linked to higher risk of psychological distress, symptoms burden and decreased QOL after treatment among HNC survivors [18]. A study done by Yu et al. evaluating gaps in treatment and surveillance in head and neck cancer at a single safety net hospital demonstrated that 69 % of patients remained adherent to post treatment surveillance at 1 year. This rate subsequently decreased to 47 % by year 5 [19]. These statistics demonstrate the suboptimal follow up for surveillance care in the safety net HNC population often driven by social vulnerabilities relating to health access, socioeconomic status, transportation, and social support. We believe that it is important to adapt treatment protocols to better serve the needs of this population.

Yao et al. reported an average duration of treatment of 79 days in their home treatment group compared to 109 days in their hybrid (facility and home based) treatment group [7]. Considering that nearly 60 % of our patient cohort was continuing their exercise regimen at a 6-month time frame, this not only demonstrates feasibility of this exercise program but also improvement in duration of home based head and neck exercise program compared to prior studies. This is important due to the long-term implications of lymphedema including increasing long-term fibrosis and resultant worsening functional impairment [4].

There are limited assessments of the impact of HNL therapy on patient diet in the current literature. Our study showed improvement over time in patient diet following the initiation of treatment with significant improvement seen at 6 months and 9 months. All 12 patients who presented for the 9 month follow up survey reported consuming regular diets. It is important to note that there is potential for improvement in diet with time following completion of radiation in the absence of therapy. Further studies including a control group of patients who did not undergo HNL therapy may be beneficial to compare diet improvements over the same time intervals.

Limitations to this study include the inherent bias of retrospective data collection including missing data and misclassification of data. Severity of the lymphedema at initiation of treatment has the potential to impact perceived benefit and quality of life impact, and therefore, may make results less applicable to patients with less lymphedema burden. One of the most significant limitations to the study was our small patient population complicated by loss of patients over time. Future studies should include larger cohorts with both short- and long-term evaluation of objective and subjective measures of quality of life.

## 5. Conclusion

Home-based head and neck lymphedema treatment showed improvements in patient diet over time. Patient compliance rate demonstrates feasibility of home exercises in a tertiary care setting with a socially vulnerable patient population.

## Credit authorship contribution statement

**Kelsey Wood:** Conceptualization, Data curation, Investigation, Methodology, Resources, Writing – original draft, Writing – review & editing. **Samuel Hopper:** Investigation, Writing – original draft, Writing – review & editing. **M. Caroline Murray:** Conceptualization, Investigation, Methodology, Resources. **Josephine Alston:** Conceptualization, Methodology, Supervision. **Oishika Paul:** Formal analysis. **Gina D. Jefferson:** Writing – review & editing. **Lana L. Jackson:** Writing – review & editing. **Anne C. Kane:** Conceptualization, Investigation, Methodology, Project administration, Resources, Supervision, Writing – review & editing.

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## Declaration of competing interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

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