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Effectiveness of a Home-based Head and Neck Lymphedema Management Program: A Pilot Study

Theresa Yao, MS CF-SLP; Beth Beadle, MD PhD; C. Floyd Holsinger, MD Ⓡ; Heather M. Starmer, MA CCC-SLP, BCS-S Ⓡ

**Objective:** This study aimed to compare outcomes in patients with head and neck lymphedema receiving either a home-based lymphedema treatment program or a hybrid approach including both home-based treatment and regular clinical visits.

**Methods:** Outcomes were assessed in patients receiving head and neck lymphedema rehabilitation. Baseline measures of neck, submental, and facial edema were obtained and repeated following treatment. A home program was recommended for all patients, and those receiving hybrid care received the same recommendations as well as a visit with the lymphedema therapist for additional treatment. Their outcomes were compared using standard statistical analysis.

**Results:** Fifty consecutive individuals were included, 25 in each group. Adherence to at least 50% of recommended treatment was reported in 68% of those receiving home-based treatment and 84% of those receiving hybrid care. Significant improvement was demonstrated for 66% of patients. There was no statistically significant difference between treatment groups with regard to clinically significant improvement (P = .15). Patients receiving hybrid therapy demonstrated treatment advantages regarding facial edema (P = .037). Adherence to treatment was associated with clinical improvement (P = .047).

**Conclusions:** Comparable benefits were observed regardless of whether patients had a home-based or hybrid lymphedema treatment approach. These data suggest a home-based treatment approach may be appropriate for patients unable to participate in clinical sessions. However, for patients with significant facial edema, a hybrid approach may be preferable. Adherence was associated with better outcomes. Given these findings, future investigations should consider strategies to improve adherence to optimize the outcomes lymphedema treatment.

**Key Words:** Head and neck cancer, lymphedema, lymphedema therapy, head and neck, lymphedema, home-based treatment, adherence.

**Level of Evidence:** 3b

INTRODUCTION

According to 2019 Cancer Statistics, approximately 53,000 Americans are diagnosed with head and neck cancer (HNC) annually.1 Currently, treatment options for first line treatment of HNC include surgery, radiation, and chemotherapy. One of the common consequences of head and neck cancer and its treatment is lymphedema. Lymphedema may occur due to the interruption of the normal flow and containment of lymphatic fluid within the lymphatic system resulting in collection of lymphatic fluid in the interstitial tissue. It can be caused by surgical removal of lymph nodes, radiation, or chemoradiation therapy that may impair lymphatic vessel contractility, or vessel obstruction caused by the tumor itself.2-4 The prevalence of lymphedema after head and neck cancer treatment has been reported as high as 75%.5

Patients with head and neck lymphedema (HNL) may experience edema in both internal and external structures.3 Internal HNL can cause changes in voice, dysphagia, or difficulty breathing.2 External lymphedema may lead to functional restriction of range of motion as well as cosmetic issues which may result in dissatisfaction with appearance, negative body image, isolation, and social avoidance.3,6 Patients with HNL have higher symptom burden than their counterparts without lymphedema.3,6 Earlier detection and treatment of HNL typically leads to better outcomes in regard to regression of swelling and prevention of chronic soft tissue toxicities.7,8 If lymphedema is left untreated, the edema may progressively worsen, contributing to the development of permanent fibrosis. This can contribute to long-term functional deficits in speech, respiration, voice, and swallowing, as well as decreased quality of life and psychosocial consequences that may be irreversible.4,8 Thus, lymphedema treatment is an important component of post HNC rehabilitation.

The standard of care for lymphedema treatment, regardless of affected body site, includes risk reduction through patient education and consultation, early detection, complete decongestive therapy (CDT) in a clinical setting, and self-management at home.7 CDT is considered to be the gold standard treatment for patients with extremity lymphedema and has been adopted in
treatment of HNL. CDT typically includes manual lymphatic drainage, tissue compression with bandaging and/or garments, skin care of the affected areas, and remedial exercises for the face, throat, and neck. There has been limited evidence and examination of the effectiveness of HNL treatment. Available studies have utilized different treatment regimens that comprise some or all elements of CDT. Most of the programs studied have been designed as clinician-administered outpatient programs with some level of self-management recommended. Multiple studies have reported positive outcomes following HNL management.

Although high levels of response to treatment have been reported, there are barriers that prevent some patients from receiving or completing the recommended course of lymphedema treatment. Some common challenges include time constraints, financial barriers, transportation issues, physical limitations, and availability of certified lymphedema therapists in the geographic region of the patient. When patients are not able to participate in clinician-administered therapy sessions in the outpatient clinic, a self- (or caregiver-) administered home program is usually recommended under the guidance of the lymphedema therapist. This home program may be comprised of similar treatment elements received in clinic. Although Smith et al. reported that 58% of patients treated with only a home program demonstrated improvement in head and neck lymphedema, poor patient adherence at home may become a barrier which prevents patients from accomplishing similar outcomes to those who receive outpatient therapy.

Currently, there is limited evidence available regarding the effectiveness of home-based HNL therapy. Thus, the purpose of this study is to compare outcomes between patients treated through a home-based program and patients receiving a hybrid approach, including both at-home treatment and in-clinic treatments. The impact of treatment location on adherence and outcomes is investigated.

### MATERIALS AND METHODS

Lymphedema outcomes were retrospectively assessed in 50 patients receiving lymphedema rehabilitation following treatment for HNC. All patients referred for lymphedema therapy between October 2015 and April 2018 with baseline and follow-up measures were included for analysis. All patients were previously treated for head and neck tumors with surgical and/or radiation-based treatment with curative intent. Patients with recurrent and metastatic disease were excluded from analysis. The diagnosis of HNL was established by the referring oncology physician.

Patients referred for lymphedema management were evaluated by a trained speech-language pathologist in an outpatient clinical setting. Measures of neck, head, and facial edema were obtained at baseline, prior to implementation of lymphedema treatment and after approximately 3 months of treatment. The MD Anderson Head and Neck Lymphedema scale was used to quantify severity of tissue changes and reversibility of pitting (Table I). Measures were performed using a standard tape measure protocol previously described by Smith et al. Neck measures included circumferential measurement of the upper, mid, and lower neck, and the composite neck measure was obtained by adding these three values. Facial measures included the distance between: tragus to chin, tragus to mouth angle, mandibular angle to nasal wing, mandibular angle to inner eye corner, mandibular angle to outer eye corner, mental protuberance to inner eye corner, and mandibular angle to mental protuberance. The facial composite measure was the sum of these measures. Head measures were obtained through measurement of the longitudinal circumference of the head. A composite measure of response to treatment averaged the percentage change in neck measures, submental measures, and facial measures. Clinically significant change was determined based on a reduction in the MD Anderson Stage and/or a change in the composite measure of 2% or more, as previously reported in the literature.

All patients were deemed appropriate for lymphedema therapy by the referring oncologist and the treating speech-language pathologist. A recommendation for hybrid treatment including daily home treatment and weekly clinical visits was made for all patients. Patients unable to participate in regular clinical visits were trained in a home treatment CDT protocol including manual lymphatic drainage, compression, skin care, and basic swallowing exercises. Those receiving hybrid care completed the same home program, but also met with the lymphedema therapist every 1–2 weeks for clinician-administered treatment. During clinical treatment sessions, additional time was provided to review home treatment technique as well as to apply clinician manual lymphatic drainage. Clinical treatment sessions ranged from 30–45 minutes in duration. All patients were treated by a single clinician and provided with the same materials to support their home treatment protocol.

Study variables collected included basic patient demographics (age and sex), tumor characteristics (primary site, T stage, N stage, M stage), all cancer treatments received (surgery, radiation, chemotherapy), as well as primary cancer treatment. Lymphedema characteristics (MD Anderson HNL rating, tape measures, and composite scores) were recorded. Patients were stratified as home only treatment if they received three or fewer clinical treatment sessions and hybrid treatment if four or more clinical sessions were completed. Sensitivity analysis was performed with a treatment cut point of two visits with no significant differences observed. Other treatment factors that may impact outcomes including patient-reported home adherence and availability of caregiver support were obtained through telephone interviews. Consistent with prior investigations, patients who completed at least 50% of the recommended treatment were considered adherent. Statistical analysis was performed using Prism GraphPad. Standard statistical analysis was performed and included descriptive statistics such as Chi-squared analysis for bivariate associations and T-test analysis for continuous variables. $P$ value < .05 was used as the threshold for statistical significance. This protocol was reviewed and approved by the institutional review board.
RESULTS

A total of 50 consecutive individuals with both pre- and post-treatment assessments were included in analysis. Demographic details can be found in Table II. Average duration of treatment was 99 days (SD = 54.6; range 22–266 days). There were 25 patients in each treatment group. Early T-stage (<T2) and N-stage (<N2) were noted in 66% and 52% of participants, respectively. There was no significant difference between treatment groups in regards to age, sex, T-stage, or N-stage. Surgery was performed for 66% of participants while 34% underwent nonoperative treatment only. While more patients in the hybrid treatment group had surgery as part of their treatment, this failed to reach statistical significance ($P = .07$). All patients received external beam intensity-modulated radiation therapy either as primary or adjuvant treatment. Patients in the hybrid therapy group were more likely to present with more advanced lymphedema at baseline ($P = .007$). Patients in the hybrid therapy group had a longer average duration of treatment (109 days) compared to the home treatment group (79 days; $P = .047$).

Patients in both treatment groups demonstrated improvements in lymphedema measures (Table III). Clinically significant improvement was documented for 66% of participants with no significant difference between treatment groups ($P = .15$). The average percent of reduction of lymphedema across treatment groups was 2.11% (range $-2.27$ to $-10.93$%). There was no significant difference in the overall percent reduction of lymphedema between treatment groups ($P = .587$). Patients receiving hybrid therapy demonstrated treatment advantages in regard to facial edema in contrast to those receiving only home-based care ($P = .037$). Adherence of at least 50% of recommended treatment was reported in 68% those receiving home-based treatment and 84% of those receiving hybrid care. Adherence was associated with higher levels of clinically significant improvement with 72% of adherent patients demonstrating clinical improvement. In contrast, only 28% of those who were not adherent demonstrated clinically significant change ($P = .047$). Patients in both treatment groups were equally likely to have caregiver assistance with their home treatment protocol.

DISCUSSION

Given the high prevalence of lymphedema following HNC treatment and its potential negative effect on body image as well as speech and swallowing functions, it is
important to identify lymphedema early and provide effective treatment in a timely manner. Previous studies have shown improvement in lymphedema outcomes in patients receiving clinician-administered outpatient programs.\textsuperscript{4,8–11} When patients encounter challenges such as transportation restrictions or limited availability of certified lymphedema therapists in their geographic region,\textsuperscript{8} a home program is often recommended, although data is limited regarding the effectiveness of home-based HNL treatment. Smith and colleagues\textsuperscript{8} examined home-based lymphedema treatment with results suggesting high response rate to the treatment, although patients receiving outpatient lymphedema therapy demonstrated more gains than those who received only home-based treatment.

The current study compared the outcomes of HNL treatment administered through a home-based lymphedema program to a hybrid approach with both clinical and home treatment. Improvements appeared more robust in patients receiving hybrid-based lymphedema therapy, although overall measures did not show a significant difference between the treatment groups. A contributing factor may be the longer duration of treatment observed in those individuals undergoing a hybrid treatment approach. It is possible that with additional treatment time, those individuals on a home-based treatment program may have demonstrated greater improvement. Despite a lack of statistically significant difference in overall edema between groups, patients who received hybrid treatment demonstrated better outcomes in reduction of facial edema, suggesting that patients with facial edema may benefit from a more clinician-directed approach.

Notably, patients in the hybrid therapy group were more likely to present with more advanced lymphedema at baseline. This finding raises the question as to whether patients with more advanced stage lymphedema at baseline will demonstrate comparable outcomes whether receiving home-based or hybrid treatment. The current study is under-powered to evaluate this question, however, it does raise the concern that the findings of this study may not be generalizable to patients with more advanced stage lymphedema. As was noted in patients with facial edema, there may be benefit to clinical treatment in this specific subpopulation of patients with HNL.

In addition to comparing the outcomes between treatment groups, we investigated the relationship between adherence and outcomes, regardless as to which treatment model was employed. Adherence to treatment recommendations was associated with a higher percentage of patients achieving clinically significant treatment benefits. Patient adherence was higher in those receiving hybrid care than those receiving home-based treatment. This finding may suggest that accountability to the clinician during more frequent visits may help to enhance adherence. Alternatively, this finding may reflect that those patients receiving hybrid care had more opportunity to clarify treatment techniques, thus enhancing patient/caregiver comfort with home treatment. Future investigations may benefit from evaluation of factors contributing to adherence to facilitate new treatment strategies to optimize adherence.

As comparable treatment success was shown between groups in this study, we suggest that utilization of patient/caregiver administered home therapy may provide meaningful advantages to some patients with lymphedema. Patients facing barriers such as limited availability of local therapists, difficulty with transportation, or lack of outpatient therapy benefits may be excellent candidates for a home-based lymphedema treatment program. In an era of healthcare cost containment, use of lower-cost treatment strategies such as home-based exercise programs may be beneficial in some scenarios. However, there are some factors that must be considered for provision of an effective home-based program. One of the major challenges to home-based treatment is patient adherence. Providing sufficient education at the beginning of treatment and selecting appropriate methods to monitor and maintain adherence may be critical for achievement of optimal treatment outcomes. It is critical for therapists to provide adequate training to establish patient/caregiver competency before they initiate the home program. It may also be beneficial to schedule touch points between therapists and patients on a home program to ensure accuracy in applying treatment techniques at home, although implementing such outreach strategies can be challenging in the fee for service model of healthcare. Future studies may consider use of telehealth or similar modalities to enhance home-based rehabilitative care.

A number of limitations must be acknowledged in this study. First, as the data collected in this study were from a retrospective chart review, we were unable to control for variables such as severity of baseline lymphedema and presence of caregiver support, both of which may have influenced outcomes. As those patients receiving hybrid treatment were more likely to have advanced MD Anderson stage lymphedema at baseline, they had more potential for a reduction in lymphedema severity grade. Another significant limitation is in regard to adherence data. This data was subject to recall bias and social desirability bias as we contacted patients by phone call after completion of treatment. Thus, there is potential that patients may have over- or underestimated adherence. However given that this method of data collection was similar for patients in both groups, we expect the magnitude of bias to be similar in their reports. Future investigations would benefit from a more structured method of measuring adherence. It is also suggested that future investigations include a measure of patient perceived improvement following treatment to account for functional benefits.

CONCLUSIONS

The results from this current study suggest that in a selected group of patients with HNL, a home-based treatment strategy may be appropriate if the patient is unable to participate in clinical sessions. Patients with facial edema or more advanced stage lymphedema may benefit from a more clinician directed approach. Overall, adherence appears to be a better predictor of outcome than treatment modality. Adherence appears more favorable
in patients receiving some level of clinician intervention suggesting that future investigations should consider strategies to increase adherence and optimize the outcomes of home-based treatments for lymphedema.

BIBLIOGRAPHY