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Original Article

Establishing a Comprehensive Lymphedema Program in a Rural Region

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ABSTRACT

Background Comprehensive lymphedema programs (CLPs) have recently been established at several large academic medical centers. However, little has been published regarding implementation of multidisciplinary lymphedema programs serving predominantly rural and medically underserved populations. We describe our early experience developing a CLP and highlight lessons that may facilitate implementation in similar settings.

Methods We performed a retrospective review of all patients referred to our CLP from November 2021 to April 2024. Patients without complete electronic medical record information were excluded. Financial analyses were limited to patients who underwent operative intervention and completed all insurance preauthorization and appeal processes.

Results A total of 321 patients were referred to our CLP, of whom 190 underwent complete evaluation. Seventy-three patients (38.4%) underwent operative intervention, including 43 (58.9%) who underwent immediate lymphatic reconstruction (ILR). Among patients undergoing delayed lymphatic reconstruction (DLR), 60% underwent physiologic and 26.7% underwent debulking procedures. The program demonstrated sustained growth throughout the study period with expansion into a multistate referral network. Insurance reimbursement remained limited, with insurers covering 29.7% of surgeon fees and total reimbursement averaging 35.7% of billed surgeon charges.

Conclusion Development of a CLP serving a predominantly rural and medically underserved population region is feasible through multidisciplinary collaboration, strategic resource allocation, and adaptation to local resources. The principles described may provide a practical framework for developing sustainable CLPs and expanding access to specialized lymphedema care in similar settings.

Keywords comprehensive lymphedema program, rural health, breast cancer-related lymphedema, lymphedema surgery, reimbursement, program implementation

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Introduction

Lymphedema is a chronic, progressive disease affecting millions of patients worldwide, and is associated with substantial physical, functional, psychosocial, and economic morbidity. Patients undergoing treatment for cancer are particularly susceptible to secondary lymphedema following lymph node dissection, radiation therapy, and systemic therapies.[1,2] The incidence of cancer-related lymphedema varies considerably across malignancy types and treatment modalities, with reported rates ranging from 2 to 74% following breast cancer treatment, 8 to 45% after gynecologic and urologic malignancies, 71 to 90% following head and neck cancer treatment, and 2 to 29% after melanoma.[1] Other causes of lymphedema include trauma, congenital lymphatic abnormalities (primary lymphedema), and chronic venous insufficiency resulting in phlebolymphedema, an increasingly recognized cause of lower extremity lymphedema.[3,4]

Although universally accepted definitions and diagnostic criteria for lymphedema remain lacking,[1,5] contemporary evaluation typically incorporates limb circumference measurements, perometry or volumetric assessment, bioimpedance spectroscopy, patient-reported outcome measures, and imaging modalities such as indocyanine green (ICG) lymphography and magnetic resonance lymphography. Recent advances in microsurgical techniques and multidisciplinary care have substantially improved both the prevention and treatment of lymphedema.[3,4,6–10] Preventative

approaches include lymphovenous anastomosis (LVA) performed at the time of lymph node dissection for malignancy, termed immediate lymphatic reconstruction (ILR), which has consistently been shown to reduce the incidence of cancer-related lymphedema.[10–23] Treatment of established lymphedema, referred to as delayed lymphatic reconstruction (DLR), includes physiologic procedures such as LVA and vascularized lymph node transfer (VLNT), as well as debulking procedures including liposuction or direct excision for advanced disease.[10,20,21,24–28]

In parallel with advances in lymphatic surgery, multidisciplinary comprehensive lymphedema programs (CLPs) have been established to provide coordinated evaluation, conservative management, surveillance, and surgical care. Previous studies out of larger, metropolitan programs have detailed early experiences with the creation of such programs and have served as examples for other centers to follow suit.[8,15,27–31] Recent studies have also focused on the financial implications of building such programs that include surgical approaches.[32–35] While these centers have served as a model for the creation of our institution's CLP, our program is unique in the region and patient population it serves. No prior studies to our knowledge have described the creation and initial experience of a CLP in a mostly rural, under-resourced Appalachian region.

Although previous reports describing development of CLPs at large metropolitan academic centers have provided an important framework for program development,[8,15,29–33] little guidance exists for institutions serving predominantly rural and medically underserved populations. These regions frequently face unique barriers to establishing CLPs, including limited access to certified lymphedema therapists (CLTs) and specialty care, greater travel distances, less established referral pathways, and financial constraints that collectively delay diagnosis, limit access to multidisciplinary care, and hinder program implementation.[36–40] Our institution serves a predominantly rural Appalachian referral region, presenting challenges distinct from those encountered at larger urban centers.

The purpose of this study is to describe our institution's early experience developing a CLP. Specifically, we sought to characterize program growth, referral patterns, patient demographics, operative management, financial considerations, and implementation strategies while highlighting lessons learned that may facilitate development of similar programs in other underserved or under-resourced regions.

Patients and Methods

Study Design and Data Collection

We performed a retrospective review of all patients referred to our institution's CLP from program inception in November 2021 through April 2024. Patients were identified from a prospectively maintained institutional lymphedema registry. Demographic characteristics, clinical variables, treatment details, and outcomes were collected through retrospective review of electronic medical records. Financial analyses were limited to patients who underwent operative intervention and had completed all insurance adjudication, appeals, and reimbursement processes without outstanding claims. Geographic distribution maps of the patients evaluated in the lymphedema clinic were created using ArcGIS software (ERSI 2023. ArcGIS Pro Desktop: Release 3.3. Redlands, CA: Environmental Systems Research Institute).

Program Development and Infrastructure

The CLP was established at our institution in Knoxville, Tennessee, in November of 2021 to provide multidisciplinary evaluation, surveillance, and treatment of patients at risk for or diagnosed with lymphedema. The program was modeled after the multidisciplinary framework developed by the Boston Lymphatic Center, with adaptations to address the unique challenges of delivering comprehensive lymphedema care in a predominantly rural Appalachian referral region.[15,16,27,35,41]

Prior to establishment of the CLP, institutional resources included a breast oncology nurse practitioner who also served as the initial lymphedema coordinator, two non-dedicated CLTs, ICG lymphography, standard microsurgical instrumentation, and operating microscopes routinely used for reconstructive microsurgery. During recruitment of the senior author (S.B.), institutional leadership committed dedicated resources to support development of the CLP, including acquisition of a high-magnification operating microscope capable of supermicrosurgery, supermicrosurgical instrumentation, a specialized hand table for LVA, two bioimpedance spectroscopy devices (SOZO; ImpediMed, Carlsbad, CA), one perometer, and dedicated research coordinator support. Securing these resources during faculty recruitment established the infrastructure necessary to support comprehensive surgery from program inception. Following completion of the study period, the multidisciplinary team was further expanded to include a dedicated nurse practitioner who served as the lymphedema coordinator. As this addition occurred after the study period, it was not included in the present analysis.

The multidisciplinary team included plastic surgery, surgical oncology, radiation oncology, medical oncology, vascular surgery, cardiology, radiology, nutrition, and certified lymphedema therapy. A dedicated research coordinator developed and maintained a prospective registry while supporting outcomes research and quality improvement initiatives.

Educational outreach through regional lectures, multidisciplinary conferences and tumor boards, and provider education initiatives were performed throughout program development to increase awareness of lymphedema, facilitate earlier referral, and strengthen collaboration with community healthcare providers and CLTs across the region.

Given the limited personnel and institutional resources available during early program development, we intentionally prioritized patients with breast cancer–related lymphedema and those undergoing axillary lymph node dissection. This strategy leveraged established multidisciplinary breast oncology referral pathways, focused resources on patient populations with the strongest evidence supporting preventive lymphatic surgery, and facilitated efficient early program growth.

Our program incorporates many elements common to established Lymphatic Education & Research Network (LE&RN) Centers of Excellence, including multidisciplinary care, certified lymphedema therapy, physiologic and debulking surgical options, and patient education.[42] Our experience additionally highlights the importance of regional therapy networks and coordinated referral

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pathways to extend comprehensive lymphedema care to geographically dispersed and underserved populations.

Clinical Evaluation and Treatment Protocols

Patients referred to the CLP underwent standardized multidisciplinary evaluation consisting of medical history, physical examination, limb circumference measurements, perometry, bioimpedance spectroscopy (L-Dex), and International Society of Lymphology staging. Patients considered potential surgical candidates underwent ICG lymphography to assist with disease staging and operative planning. Additional imaging studies, including nuclear medicine lymphoscintigraphy and single-photon emission computed tomography, were incorporated into the diagnostic evaluation when clinically indicated through standardized institutional imaging protocols developed in collaboration with the Department of Radiology. Following completion of the study period, the diagnostic algorithm was expanded to include magnetic resonance lymphography for select patients.

Patients undergoing ILR received baseline measurements before surgery followed by postoperative surveillance at 6 weeks, 3 months, every 6 months for 3 years, and annually thereafter using limb circumference, perometry, and bioimpedance spectroscopy. Class I compression garments (18–21 mm Hg) were prescribed immediately postoperatively and worn for a minimum of 8 hours daily until 3 months after completion of adjuvant therapy, excluding endocrine therapy. All patients were referred to a CLT at 4 weeks postoperatively.

Patients with established lymphedema were required to complete appropriate conservative therapy, including complete decongestive therapy under the care of a CLT, before consideration for DLR. Postoperative surveillance following DLR was performed at 6, 12, 18, and 24 months, after which patients transitioned to annual follow-up. Postoperative compression and physical therapy protocols were individualized according to the surgical procedure performed and patient-specific clinical needs. Patient-reported outcomes were assessed using the Lymphedema Life Impact Scale (LLIS) and the Lymphedema Quality of Life Questionnaire (LYMQOL).

Standardized postoperative rehabilitation protocols following each lymphatic procedure are summarized in **Table 1**.

Results

Patient Flow and Population Description

During the study period, 321 patients were referred to the CLP, of whom 190 underwent multidisciplinary evaluation. Patients who were not evaluated were awaiting initial consultation, cancelled scheduled appointments, or declined evaluation. Among evaluated patients, 73 (22.7%) ultimately underwent operative intervention.

Patient demographics and disease characteristics are summarized in **Table 2**. The mean age at time of referral was 58.5 years, with a mean body mass index (BMI) of 29.7 kg/m^2. Most patients were female (93.7%), and presented with cancer-related lymphedema, predominantly following treatment for breast cancer. Upper extremity lymphedema represented most referrals, while few patients presented with primary lymphedema or phlebolymphedema during the study period.

Chronic Lymphedema

Of the evaluated patients, 142 (74.7%) were diagnosed with chronic lymphedema (**Table 3**). Secondary lymphedema accounted for 98.6% of cases, with breast cancer–related upper extremity lymphedema representing the most common presentation (74.6 and 78.9%, respectively). The mean duration of lymphedema before presentation was 45.8 months. Notably, 74 patients (52.1%) were referred to a CLT for the first time following multidisciplinary evaluation. Twenty-nine patients (20.4%) underwent operative management, 94 (66.2%) were managed nonoperatively, and 19 (13.4%) were scheduled for surgical intervention that had not yet been performed at the time of data collection. The most common reasons for nonoperative management included unsuccessful optimization for surgery due to limited adherence to conservative therapy or barriers to accessing lymphedema care, insurance-related barriers, medical comorbidities, mild disease controlled with conservative management, and the absence of suitable lymphatic targets for LVA on ICG lymphography.

Operative Interventions and Early Outcomes

Of the 190 patients evaluated in clinic, 73 (38.4%) underwent operative intervention, including 43 (58.9%) who underwent ILR and 30 (41.1%) who underwent DLR (**Table 4**). The mean time from referral to surgery was 17.6 days for the ILR group and 117.3 days for the DLR group. Among patients undergoing DLR, the mean duration of lymphedema before surgery was 58.1 months.

Within the ILR group, one patient (2.3%) had no suitable target for LVA and underwent ICG lymphography alone. In the DLR cohort, 11 patients (36.7%) underwent therapeutic LVA, 7 (23.3%) underwent VLNT, 8 (26.7%) underwent debulking procedures, and 10 (33.3%) underwent ICG lymphography alone. Twelve patients (40.0%) in the DLR group had no suitable targets for LVA identified on ICG lymphography because of advanced disease.

Although not a primary objective of this study, a retrospective analysis of early surgical outcomes was performed. Outcome analyses were limited to patients who had reached the respective follow-up intervals at the time of data collection. Among the 27 ILR patients with complete 12-month follow-up, the incidence of lymphedema was 3.7%, with a mean change in L-Dex of 4.5. Among the 14 ILR patients with completed 24-month follow-up, one developed subclinical lymphedema, and one developed stage 1 lymphedema, both of whom were successfully managed with nonoperative treatment.

Among the DLR cohort, 11 patients had complete 24-month postoperative follow-up. At 2 years, three (27%) patients no longer required compression garments. The mean reduction in arm circumference was 2.5 cm, and the mean improvement in L-Dex was 11.3. Patient-reported outcomes were assessed using the Lymphedema Life Impact Scale (LLIS) and the Lymphedema Quality of Life Questionnaire (LYMQOL). Mean LLIS overall quality-of-life scores improved from 6.9 to 7.6 (0–10 scale, with higher

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Table 1 Standardized institutional postoperative rehabilitation protocols following lymphatic surgery

Procedure	Early postoperative compression	Lymphedema therapy	Postoperative surveillance	Long-term compression recommendations
Immediate lymphatic reconstruction (ILR)	Postoperative day 1 to 3 months after completion of adjuvant therapy (excluding endocrine therapy): Class I compression sleeve (18–21 mm Hg) worn for at least 8 hours/day	Referral to a CLT at 4 weeks postoperatively.	3 months 6 months 12 months 18 months 24 months 30 months Annually through 5 years As clinically indicated thereafter	Compression during high-risk activities to reduce the risk of lymphedema
Lymphovenous anastomosis (LVA)	Postoperative day 0 to 4 weeks: Velcro compression wrap with foam padding, 35–40 mm Hg, with bandaging as needed Weeks 4–12: Flat-knit Class II compression garment	Resume CDT 2–4 weeks postoperatively Initiate pneumatic compression 4 weeks postoperatively, as indicated	3 months 6 months 12 months 18 months 24 months Annually thereafter	Compression regimen individualized according to clinical response
Vascularized lymph node transfer (VLNT)	Postoperative day 1 to 2 weeks: Loose compression with elastic bandages or a Velcro compression wrap Weeks 2–6: Velcro compression wrap with foam padding, 25–30 mm Hg Avoid direct compression over the transferred lymph node flap during the first 6 weeks (maximum 10–15 mm Hg)	Resume CDT 6 weeks postoperatively	3 months 6 months 12 months 18 months 24 months Annually thereafter	Compression regimen individualized according to clinical response
Debulking procedure	Postoperative day 0 to 4 weeks: Velcro compression wrap with foam padding, 35–40 mm Hg, with bandaging as needed Weeks 4–12: Flat-knit Class II compression garment	Resume CDT within 1 week postoperatively	3 months 6 months 12 months 18 months 24 months Annually thereafter	Ongoing daytime and nighttime compression initially, gradually reduced based on edema control

Abbreviations: CDT, complete decongestive therapy; CLT, certified lymphedema therapist.

scores indicating better quality of life), while mean LYMQOL scores improved from 1.7 to 0.3 (0–4 scale, with lower scores indicated better quality of life; **Fig. 1**).

Program Growth

Clinic evaluation volume and operative volume increased progressively throughout the study period, despite fluctuations related to personnel and resource availability (**Fig. 2**). Referral patterns also expanded geographically, evolving from a primarily local catchment area to a multistate referral network across Appalachia and the southeastern United States (**Fig. 3**).

Financial Data

Insurance preauthorization was obtained for all surgical cases. When preauthorization was not required by the insurance carrier, predetermination was requested to confirm coverage, establish medical necessity, and estimate out-of-pocket costs. The Current Procedural Terminology (CPT) codes used are listed in **Table 5**.

Among the 73 patients who underwent operative intervention, completed financial data were available for 66 (90.4%; **Table 6**), including 43 patients (65.2%) who underwent ILR and 23 (34.8%) who underwent DLR. The most common insurance carrier in the ILR group was Blue Cross Blue Shield (39.5%). Within the DLR group Blue Cross Blue Shield (30.4%) and Cigna (30.4%) were the most common insurance carriers.

Insurance reimbursement was partial for 40 patients (93.0%) in the ILR group and 19 (82.6%) in the DLR group. No patients had full reimbursement. Despite insurance preauthorization or predetermination, one patient (2.3%) in the ILR group and four patients (17.4%) in the DLR group had no insurance reimbursement. A patient contribution toward the surgeon's fee was required in 6 ILR patients (14.0%) and 10 DLR patients (43.5%). Across both cohorts, the mean surgeon fee charged was $4,439.49. Insurance reimbursed a mean of $1,221.27, while patients paid a mean of $36.15, resulting in a mean total reimbursement of $1,257.42. Insurance covered a mean of 31.3% of the surgeon fee in the ILR group and 26.7% in the DLR group. Overall, the mean percentage of surgeon fee received was 33.8% for ILR and 39.3% for DLR.

The 66 patients with completed financial data were further stratified by year of surgery (**Table 7**). The mean surgeon fee charged declined from $5,446.04 in 2022 to $3,236.15 in 2024.

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Table 2 Descriptive summary of patients evaluated in lymphedema clinic after referral

Variable	Patients evaluated in lymphedema clinic (*n* = 190)	Operative intervention performed (*n* = 73)	Awaiting planned operative intervention (*n* = 19)	Nonoperatively managed (*n* = 98)
Age at time of referral (years)[a]	58.5 (13.0)	55.2 (14.0)	61.2 (12.7)	60.4 (11.9)
Sex				
Female	178 (93.7%)	69 (94.5%)	16 (84.2%)	93 (94.9%)
Male	12 (6.3%)	4 (5.5%)	3 (15.8%)	5 (5.1%)
Race/ethnicity				
White	180 (94.7%)	65 (89.0%)	19 (100%)	96 (98.0%)
Black	6 (3.2%)	5 (6.8%)	0 (0.0%)	1 (1.0%)
Hispanic	1 (0.5%)	1 (1.4%)	0 (0.0%)	0 (0.0%)
Asian	0 (0.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)
Other	3 (1.6%)	2 (2.7%)	0 (0.0%)	1 (1.0%)
Body mass index (kg/m^2)[a]	29.7 (6.5)	29.0 (5.5)	27.1 (4.7)	30.8 (7.3)
Tobacco use				
Never smoker	138 (72.6%)	55 (75.3%)	15 (78.9%)	68 (69.4%)
Former smoker	36 (18.9%)	12 (16.4%)	4 (21.1%)	20 (20.4%)
Active smoker	16 (8.4%)	6 (8.2%)	0 (0.0%)	10 (10.2%)
Diabetes mellitus	27 (14.2%)	10 (13.7%)	4 (21.1%)	13 (13.3%)
Referral type				
Internal	138 (72.6%)	63 (86.3%)	14 (73.7%)	61 (62.2%)
External	52 (27.4%)	10 (13.7%)	5 (26.3%)	37 (37.8%)
Diagnosis after referral				
Primary lymphedema	2 (1.1%)	1 (1.4%)	0 (0.0%)	1 (1.0%)
Secondary lymphedema	140 (73.7%)	28 (38.4%)	19 (100%)	93 (94.9%)
Non-lymphedema	5 (2.6%)	1 (1.4%)	0 (0.0%)	4 (4.1%)
At risk for lymphedema	43 (22.6%)	43 (58.9%)	0 (0.0%)	0 (0.0%
Insurance type				
Uninsured	2 (1.1%)	2 (2.7%)	0 (0.0%)	0 (0.0%)
Medicaid	11 (5.8%)	4 (5.5%)	2 (10.5%)	5 (5.1%)
Medicare	75 (39.5%)	22 (30.1%)	8 (42.1%)	45 (45.9%)
Private insurance	102 (53.7%)	45 (61.6%)	9 (47.4%)	48 (49.0%)

Notes: Reported as count and percentage of total.
[a]Reported as mean (standard deviation).

Similarly, the mean insurance reimbursement declined from $1,267.94 in 2022 to $765.52 in 2024, while the mean total reimbursement decreased from $1,302.29 in 2022 to $786.20 in 2024. Corresponding decreases were also observed in both the percentage of surgeon fees reimbursed by insurance and the overall percentage of surgeon fee received.

Discussion

Our experience demonstrates that development of a CLP is feasible even in an under-resourced, predominantly rural region, and may provide a framework for establishing similar programs in other resource-limited and geographically underserved areas. East Tennessee is part of South-Central Appalachia, where healthcare disparities are compounded by chronic poverty, long travel distances, limited access to specialty care, and higher uninsured rates than the national average.[36,43–46] In addition, Appalachian communities are often distrustful of health systems because of previous experiences, creating additional barriers to timely diagnosis, referral, and treatment.[45,46] Consequently, successful implementation of a CLP in this setting requires not only institutional commitment but also meaningful engagement with the surrounding community.

Consistent with previously described CLPs, most of the patients treated within our program had breast cancer–related lymphedema. However, women living in rural communities often face additional barriers throughout the continuum of breast cancer care, including delayed diagnosis, limited access to specialty care, and reduced availability of rehabilitation resources.[47–51] Although this study was not designed to directly assess the underdiagnosis of lymphedema, the prolonged duration of symptoms before presentation suggests that delayed recognition and referral may

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Table 3 Descriptive summary of patients diagnosed with chronic lymphedema after referral

Variable	Diagnosed with chronic lymphedema (n = 142)
Lymphedema type	
Primary lymphedema	2 (1.4%)
Secondary lymphedema	140 (98.6%)
Secondary lymphedema etiology	
Primary lymphedema	2 (1.4%)
Breast cancer	106 (74.6%)
Non-breast cancer	22 (15.5%)
Non-cancer	12 (8.5%)
Extremities affected	
Upper extremity	112 (78.9%)
Lower extremity	28 (19.7%)
Non-extremity	1 (0.7%)
Upper and lower extremity	1 (0.7%)
Laterality of lymphedema	
Right	64 (45.1%)
Left	62 (43.7%)
Bilateral	15 (10.6%)
Non-extremity	1 (0.7%)
Duration of lymphedema (months)[a]	45.8 (71.8)
Referral type	
Internal	92 (64.8%)
External	50 (35.3%)
Certified lymphedema therapy	
Internal facility	10 (7.0%)
External facility	58 (40.8%)
First referral to certified lymphedema therapist	74 (52.1%)
Management	
Operative intervention performed	29 (20.4%)
Awaiting planned operative intervention	19 (13.4%)
Nonoperatively managed	94 (66.2%)

Notes: Reported as count and percentage of total.
[a]Reported as mean (standard deviation).

occur within our predominantly rural and medically underserved population.[37] This may also contribute to more advanced lymphatic dysfunction at presentation, as reflected by the limited availability of suitable LVA targets on ICG lymphography. Previous studies from our institution have highlighted these disparities within our regional population,[38–40,52] underscoring the need for a multidisciplinary program tailored to the unique needs of patients in rural Appalachia.

Despite the challenges associated with establishing a CLP in the region, our program demonstrated sustained growth throughout the study period. Although clinical volume fluctuated because of available resources, the overall trajectory reflected progressive expansion of both the clinic encounters and surgical procedures performed. The geographic distribution of referrals similarly broadened over time, evolving from a local to multistate referral network. As the first CLP in our region, this expansion likely reflects increasing awareness among referring providers, growing reputation of the program, and an unmet regional need for specialized lymphedema care in resource-limited and geographically underserved regions. Furthermore, this expanding referral network demonstrates that patients are willing to travel substantial distances to access specialized lymphedema care when local or regional expertise is unavailable.

Barriers and Challenges

Establishing a CLP in an under-resourced region required adaptation to multiple patient-, provider-, and system-level barriers. Consistent with previous studies, our patients frequently traveled long distances for care and often had limited access to CLTs, compression garments, and providers experienced in diagnosing lymphedema, contributing to delayed referral and treatment.[43,44,47–51] In response, we tailored our surgical decision-making and postoperative care pathways to accommodate the unique challenges faced by our patients, while maintaining high-quality care. Given the limited institutional resources, we initially prioritized patients with breast cancer–related lymphedema and focused on ILR. This strategy allowed us to concentrate resources on a well-defined, high-volume patient population with established surveillance pathways and a greater likelihood of benefiting from surgical intervention, thereby maximizing the program's early clinical impact.[53] Close collaboration with breast surgical oncologists streamlined evaluation and facilitated timely referral. Finally, intermittent staffing changes and funding limitations affected program capacity, contributing to fluctuations in patient volume despite an overall pattern of sustained growth.

Unlike many CLPs, only a small proportion of our patients received therapy from CLTs within our institution. Although this approach was initially driven by limited institutional resources, it also reflected patient preference for receiving therapy closer to home because of travel times, convenience, parking accessibility, and established relationships with community providers. Consequently, our program evolved into a collaborative regional network built on close partnership with off-site community CLTs and standardized treatment protocols to ensure consistent, high-quality care across multiple practice settings. Beyond improving patient access, this model allowed institutional resources to be strategically allocated to other critical program components, including a dedicated lymphedema coordinator and patient navigator, while fostering a robust regional network of CLTs.

Financial Sustainability

As CLPs continue to expand, financial sustainability has become an increasingly important consideration for centers offering the full spectrum of surgical lymphedema treatments. Recent studies have demonstrated substantial variability in commercial reimbursement for physiologic procedures such as LVA and VLNT, largely because of inconsistent CPT code utilization and payer policies.[33] These procedures may be undervalued relative to excisional or debulking procedures, despite growing evidence supporting their clinical and economic benefit.[33] Furthermore,

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Table 4 Descriptive summary of operative interventions performed after referral

Variable	Operative intervention performed (*n* = 73)	Immediate lymphatic reconstruction (*n* = 43)	Delayed lymphatic reconstruction (*n* = 30)
Age at time of operative intervention (years)[a]	55.4 (14.0)	53.4 (14.5)	58.3 (12.9)
Time from referral to operative intervention (days)[a]	58.6 (73.7)	17.6 (22.9)	117.3 (81.6)
Duration of lymphedema (months)[a]	23.9 (52.8)	0 (0.0)	58.1 (69.7)
Operative intervention type			
Immediate lymphatic reconstruction	42 (57.5%)	42 (97.7%)	0 (0.0%)
Therapeutic lymphovenous anastomosis	11 (15.1%)	0 (0.0%)	11 (36.7%)
Vascularized lymph node transfer	7 (9.6%)	0 (0.0%)	7 (23.3%)
Debulking procedure	8 (11.0%)	0 (0.0%)	8 (26.7%)
Indocyanine green lymphangiography only	11 (15.1%)	1 (2.3%)	10 (33.3%)
Number of lymphovenous anastomoses performed[a]	3.0 (1.4)	2.9 (1.3)	3.6 (1.8)
Targets for bypass noted on ICG			
No	13 (28.3%)	1 (2.3%)	12 (40.0%)

Abbreviation: ICG, indocyanine green.
Notes: Reported as count and percentage of total.
[a]Reported as mean (standard deviation).

ILR has been shown to be cost-effective in patients undergoing axillary lymph node dissection because prevention of lymphedema offsets the additional costs of microsurgical reconstruction.[35] Our study complements these findings by providing real-world reimbursement data that illustrate the financial environment under which emerging CLPs currently operate. In the absence of standardized CPT coding practices and consistent payer policies, reimbursement for physiologic lymphatic surgery remains

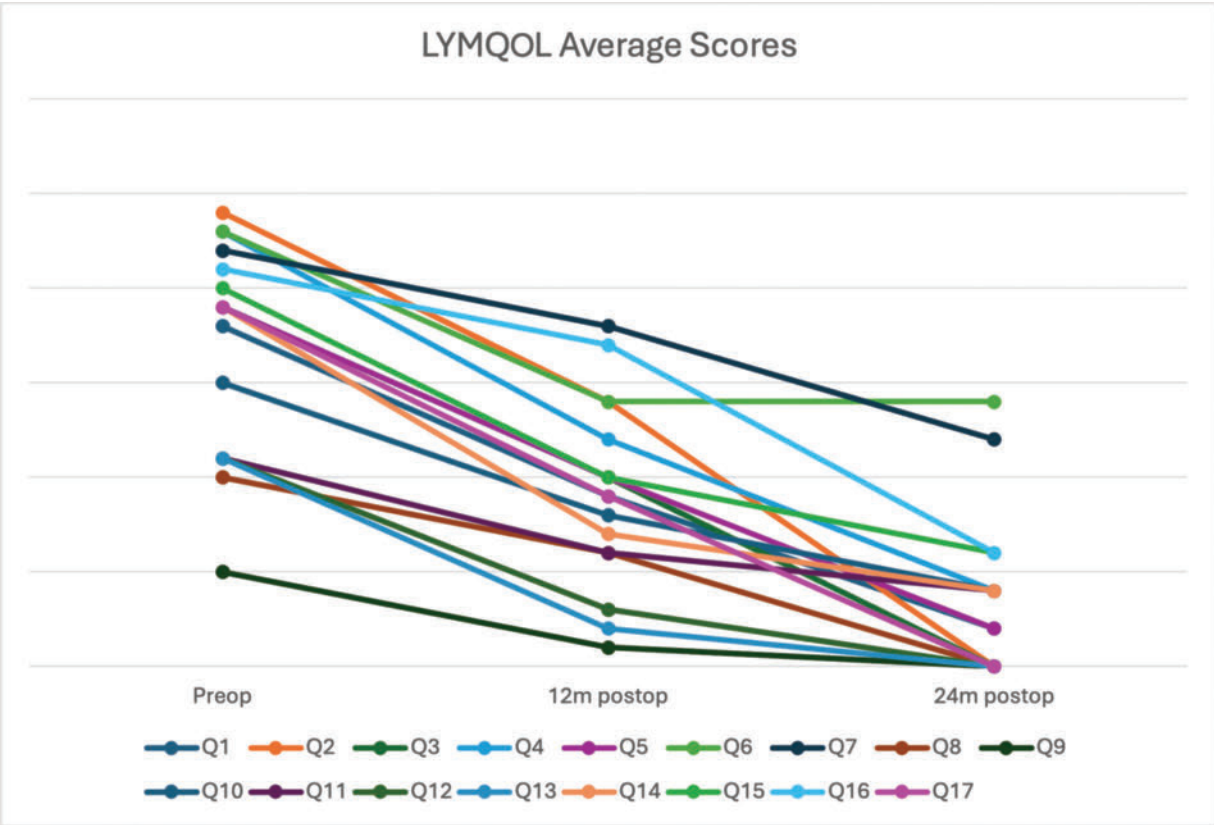


Fig. 1 Lymphedema Quality of Life Questionnaire (LYMQOL) scores 12 and 24 months postoperatively in delayed lymphatic reconstruction (DLR) patients.

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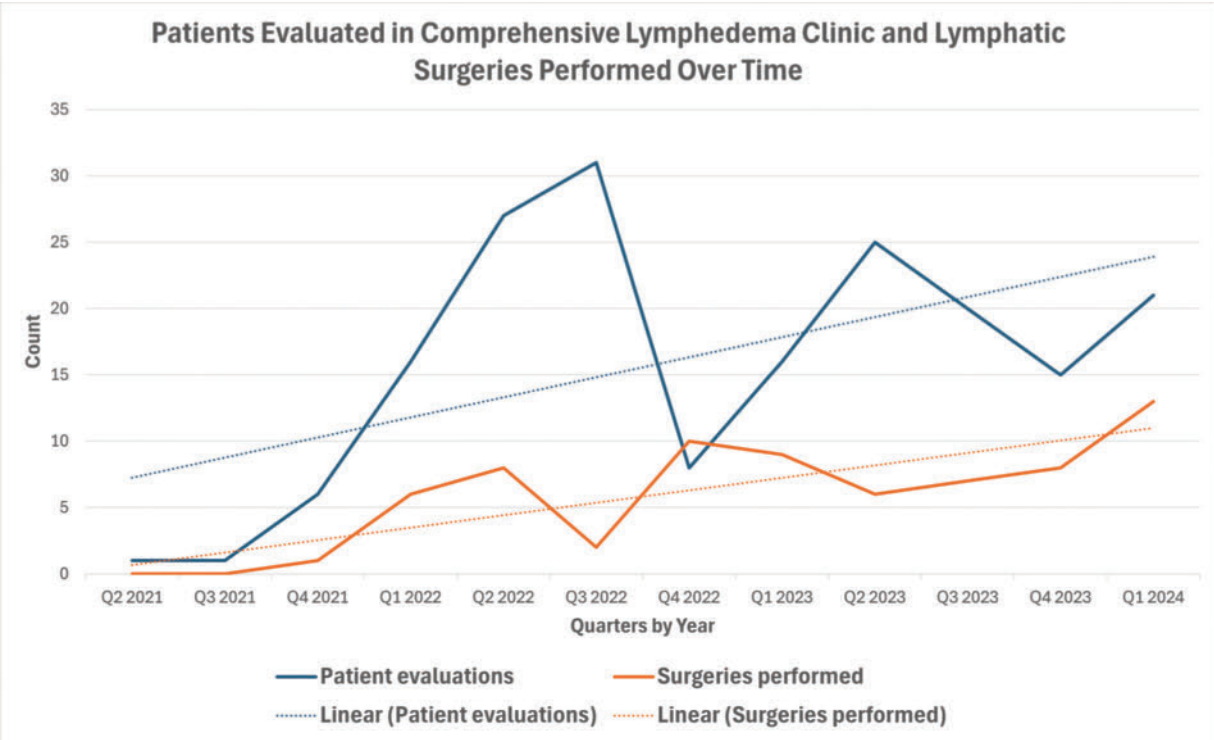


Fig. 2 Patients evaluated in the comprehensive lymphedema clinic with lymphatic surgeries performed over time.

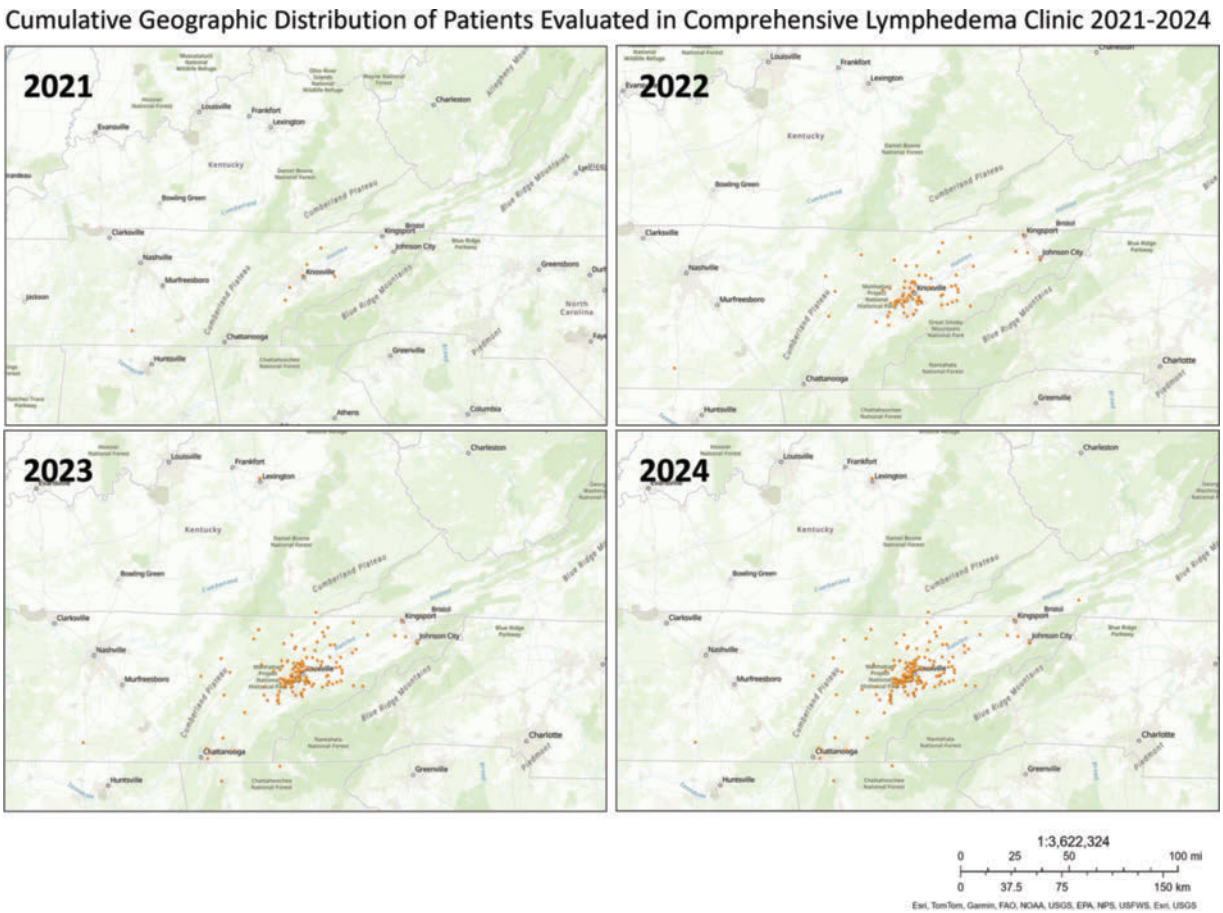


Fig. 3 Cumulative geographic distribution of patients evaluated in the comprehensive lymphedema clinic over time.

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Table 5 Current Procedural Terminology (CPT) codes used for insurance preauthorization and billing

CPT code	Description of procedure
38790	Indocyanine green (ICG) lymphangiography
35206	Repair of blood vessel, upper extremity
35226	Repair of blood vessel, lower extremity
35236	Repair of blood vessel with vein graft, upper extremity
49906	Omentum free flap
15758	Free fascial flap
15836	Lipectomy upper extremity
15832	Lipectomy thigh
15833	Lipectomy leg

highly variable, creating challenges for the long-term sustainability of CLPs.

The experience of the Boston Lymphatic Center illustrates the value of collaboration among clinicians, professional organizations, and third parties in developing standardized coverage policies.[34] However, similar policies have not been widely adopted, leaving many emerging CLPs without consistent reimbursement pathways. Although Blue Cross Blue Shield was the most common carrier in our cohort, policies established in other states did not translate into improved coverage or reimbursement within our region. Wider adoption of standardized coverage policies for lymphatic surgery, including ILR, will be critical to improving patient access and ensuring the long-term sustainability of CLPs, particularly in under-resourced settings.

Importantly, the financial sustainability of a CLP should not be evaluated solely based on professional fee reimbursement. The overall value of these programs to a healthcare system likely extends beyond individual surgical procedures through multidisciplinary care, downstream utilization of ancillary services, strengthened referral networks, and enhanced institutional visibility as a regional or national referral center. In addition, positive patient experiences may improve patient retention within the health system and facilitate referrals from patients, families, and community providers. Although these broader institutional benefits were not evaluated in the present study, they represent important considerations when assessing the long-term sustainability and value of CLPs and warrant further investigation.

Key Lessons for Program Development

Our early experience demonstrates that establishing a CLP in an under-resourced and predominantly rural region is achievable but

Table 6 Financial summary for patients who have undergone operative intervention with complete available insurance data

Variable	Completed financial information available after operative intervention (*n* = 66)	Immediate lymphatic reconstruction (*n* = 43)	Delayed lymphatic reconstruction (*n* = 23)
Insurance carrier			
Uninsured	2 (3.0%)	2 (4.7%)	0 (0.0%)
Blue Cross Blue Shield	24 (36.4%)	17 (39.5%)	7 (30.4%)
Humana	9 (13.6%)	4 (9.3%)	5 (21.7%)
Medicare	12 (18.2%)	9 (20.9%)	3 (13.0%)
United	9 (13.6%)	8 (18.6%)	1 (4.3%)
Cigna	9 (13.6%)	2 (4.7%)	7 (30.4%)
Aetna	1 (1.5%)	1 (2.3%)	0 (0.0%)
Insurance reimbursement			
Uninsured	2 (3.0%)	2 (4.7%)	0 (0.0%)
No reimbursement	5 (7.6%)	1 (2.3%)	4 (17.4%)
Partial reimbursement	59 (89.4%)	40 (93.0%)	19 (82.6%)
Full reimbursement	0 (0.0%)	0 (0.0%)	0 (0.0%)
Portion of surgeon fee was paid by patient			
No	50 (75.8%)	37 (86.0%)	13 (56.5%)
Yes	16 (24.2%)	6 (14.0%)	10 (43.5%)
Surgeon fee charged (US dollars)[a]	$4,439.49 (3,779.04)	$4,474.16 (2,563.66)	$4,374.67 (5,444.28)
Amount covered by insurance (US dollars)[a]	$1,221.27 (1445.45)	$1,269.59 (864.26)	$1,130.94 (2,175.76)
Amount paid by patient (US dollars)[a]	$36.15 (99.95)	$20.52 (80.40)	$65.38 (125.72)
Total amount received (US dollars)[a]	$1,257.42 (1,495.43)	$1,290.11 (858.90)	$1,196.31 (2,278.80)
Percentage of surgeon fee covered by insurance[a]	29.7% (18.9)	31.3% (17.4)	26.7% (21.5)
Percentage of surgeon fee received[a]	35.7% (20.9)	33.8% (19.7)	39.3% (23.0)

Notes: Reported as count and percentage of total.
[a]Reported as mean (standard deviation).

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Table 7 Financial summary for patients who have undergone operative intervention with complete available insurance data by year

Variable	2021 (*n* = 1)	2022 (*n* = 24)	2023 (*n* = 28)	2024 (*n* = 13)
Surgeon fee charged (US dollars)	$5,880.00 (0)	$5,446.04 (4,075.86)	$4,083.97 (3,999.64)	$3,236.15 (2,336.44)
Amount covered by insurance (US dollars)	$1,251.98 (0)	$1,267.94 (1,053.18)	$1,391.77 (1,938.30)	$765.52 (663.81)
Amount paid by patient (US dollars)	$0.00 (0)	$34.35 (79.46)	$46.17 (132.21)	$20.69 (45.54)
Total amount received (US dollars)	$1,251.98 (0)	$1,302.29 (1,071.11)	$1,437.94 (2,019.87)	$786.20 (643.48)
Percentage of surgeon fee covered by insurance	21.29% (0)	30.98% (23.0)	31.79% (16.2)	23.33% (16.47)
Percentage of surgeon fee received	21.29% (0)	35.16% (24.8)	37.84% (18.8)	33.26% (18.84)

Note: Reported as mean (standard deviation).

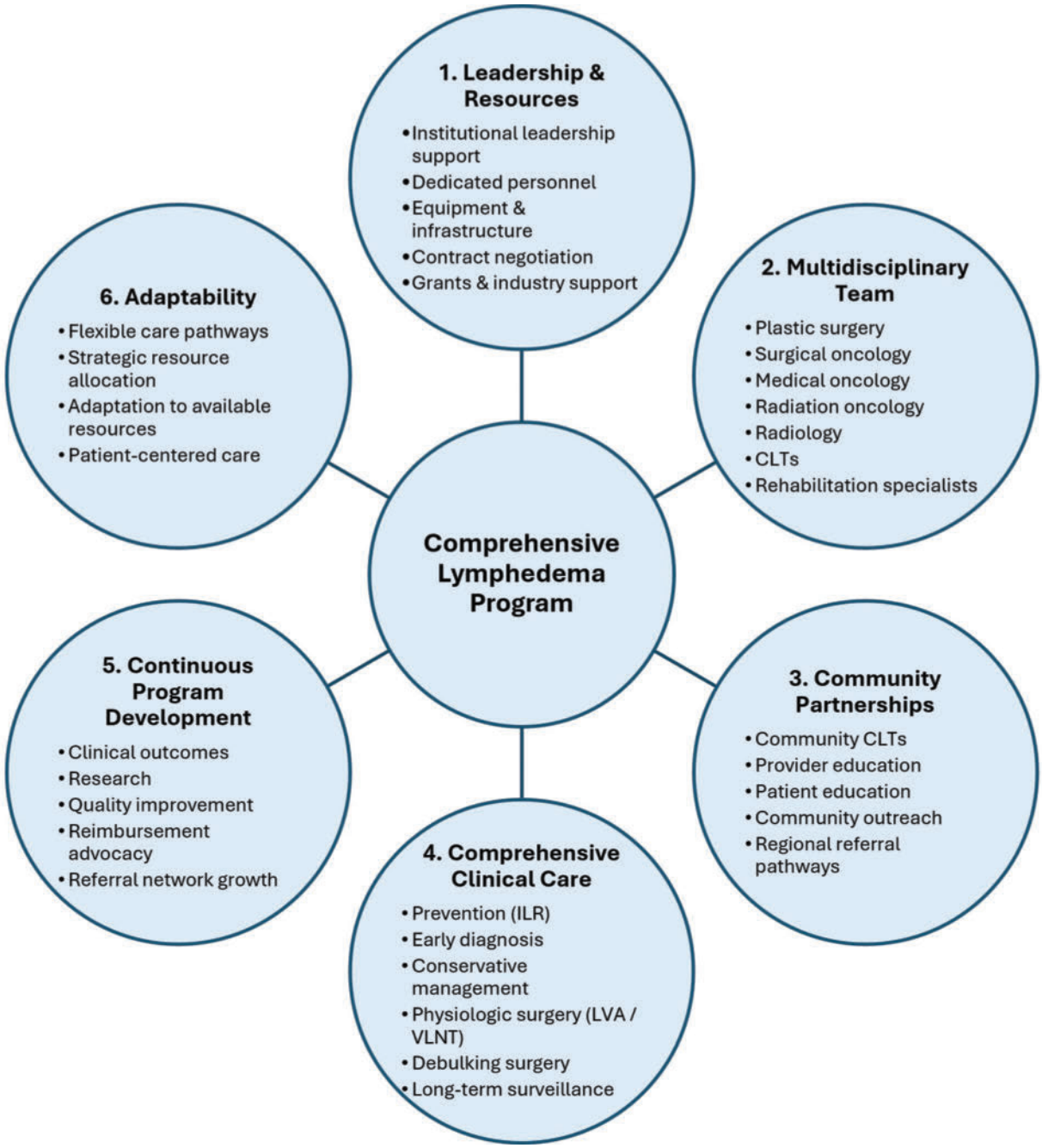


Fig. 4 Proposed framework for developing a sustainable comprehensive lymphedema program in resource-limited and geographically underserved regions. CLTs, certified lymphedema therapists; ILR, immediate lymphatic reconstruction; LVA, lymphovenous anastomosis; VLNT, vascularized lymph node transfer.

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requires strategic planning, institutional commitment, and adaptation to available resources (**Fig. 4**). Rather than relying exclusively on institution-based CLTs, we developed close partnerships with community CLTs to optimize patient care while expanding access across the region. Community engagement and ongoing education of both providers and patients were equally important, particularly in areas where awareness of lymphedema and available treatment options remains limited. For surgeons developing new programs, recruitment and contract negotiations represent a critical opportunity to secure the personnel, equipment, protected time, and institutional resources necessary for long-term success. Beyond institutional investment, strategic pursuit of internal grant funding and philanthropic industry support can further facilitate program development. In our experience, an internal cancer institute research grant supported research coordination, while unrestricted industry funding improved access to compression garments for financially vulnerable patients and subsequently supported a dedicated research fellowship as the program matured. More importantly, successful implementation requires flexibility. Rather than replicating existing CLPs, institutions should adapt clinical pathways and resource allocation to meet the needs of their patient population while maintaining high standards of care. Furthermore, we believe that emphasizing prevention through ILR and other risk-reduction strategies is both impactful and resource-efficient. Finally, although prevention remains a cornerstone of our practice, offering the full spectrum of lymphedema care has enabled our program to serve as a regional referral center for patients requiring specialized management. The resulting growth in referral volume demonstrated the value of the program to institutional leadership, strengthened stakeholder engagement, and facilitated continued program expansion. These observations reinforce the importance of developing comprehensive, rather than procedure-specific, lymphedema programs to achieve long-term sustainability.

Limitations

This study has limitations including its retrospective nature and relatively small cohort size. The study period overlaps with the COVID-19 pandemic, which significantly impacted patient volume, staffing, and program funding during the early phases of program development. The surgical outcomes presented are promising but underpowered to extract definitive conclusions. Similarly, financial data were available for most, but not all, operative patients. In addition, other components of the program financial sustainability, including facility reimbursement and downstream revenue, were not included in our analysis because these data were not available to the authors. Future studies with larger cohorts, longer follow-up, and more comprehensive financial analyses will be important to further evaluate both clinical outcomes and long-term program sustainability.

Conclusion

The development of a CLP in an under-resourced and predominantly rural region is feasible through multidisciplinary collaboration, strategic resource allocation, and adaptation to available resources. Our experience demonstrates that partnering with community CLTs, emphasizing prevention while offering the full spectrum of lymphedema care, and fostering strong institutional and community engagement can facilitate sustainable program growth and expand access to specialized care. Although long-term financial sustainability remains an important challenge, these programs provide value that extends beyond individual surgical procedures and should be supported through continued advocacy and standardized payer policies. The accelerating adoption of insurance coverage for lymphatic surgery is an encouraging trend that may improve patient access and facilitate broader implementation of CLPs. We hope the principles described in this study provide a practical framework for other institutions seeking to establish similar programs in resource-limited and geographically underserved regions.

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Statements and Additional Information

Conflict of Interest The authors declare that they have no conflict of interest.

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