

Building a Multidisciplinary Comprehensive Academic Lymphedema Program

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Background: Lymphedema is a debilitating clinical condition predominantly affecting survivors of cancer. It adversely affects patients' quality of life and results in substantial cost burdens to both patients and the healthcare system. Specialist lymphedema care is optimally provided within integrated clinical programs that align the necessary specialties to provide patient-focused, multidisciplinary, structured, and coordinated care. This article examines our experience building a specialist lymphedema academic program.

Methods: We describe the critical components necessary for constructing a multidisciplinary comprehensive academic lymphedema program. Furthermore, lessons learned from our experience building a successful lymphedema program are discussed.

Results: Building a comprehensive academic lymphedema program requires institutional support and engagement of stakeholders to establish the necessary infrastructure for comprehensive patient care. This includes the infrastructure for outpatient clinical assessment, diagnostic investigations, radiological imaging, collection of outcomes metrics, non-surgical treatment delivered by lymphedema-specialist therapists, surgical procedures using specialized equipment, and integration of an outpatient framework for comprehensive patient evaluation during follow-up at standardized time intervals.

Conclusions: This article examines our experience building a multidisciplinary comprehensive academic lymphedema program and provides a structured roadmap to benefit others that are embarking on this mission. (*Plast Reconstr Surg Glob Open* 2020;8:e2670; doi: [10.1097/GOX.0000000000002670](https://doi.org/10.1097/GOX.0000000000002670); Published online 20 March 2020.)

INTRODUCTION

Lymphedema is a common, chronic, and debilitating condition characterized by limb swelling resulting from dysfunction of the lymphatic system, affecting ~1 in 30 people worldwide (up to 250 million people).^{1,2} In the United States over 10 million people suffer from lymphedema, with ~200,000 new cases diagnosed annually; these are predominantly iatrogenic to cancer treatment, affecting around 15% of cancer survivors,³ in particular breast⁴ and gynecologic cancer.⁵

It causes profound physical disability and negative psychosocial impact on patients, with quality of life inversely related to clinical severity.⁶ Lymphedema imposes substantial costs on patients and the healthcare system, and recently the Centers for Medicare & Medicaid Services reimbursed

conservative lymphedema management at a cost of \$498 million annually (ranking 13th among all treatments).⁷ Poorly managed lymphedema may lead to complications, including cellulitis, that can require inpatient treatment and dramatically increase the costs of care.^{8,9}

MANAGEMENT OF PATIENTS WITH LYMPHEDEMA

The management of patients with lymphedema involves multidisciplinary care with both non-surgical (conservative) and surgical approaches. The mainstay of conservative therapy is complete decongestive therapy, ideally conducted by a lymphedema-specialist physical therapist (PT).¹⁰⁻¹² For patients with persistent lymphedema despite completing a course of conservative treatment, modern surgical techniques have been demonstrated to ameliorate the symptoms and functional impairment and to reduce the incidence of cellulitis.¹³⁻¹⁹

Physiological surgery for lymphedema is more effective at reducing limb circumference/volume than conservative therapy alone.^{14,20-22} Surgical procedures, including lymphovenous bypass (LVB) and vascularized lymph node transfer (VLNT), use microsurgical techniques to restore

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Received for publication November 1, 2019; accepted January 6, 2020.

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DOI: [10.1097/GOX.0000000000002670](https://doi.org/10.1097/GOX.0000000000002670)

Disclosure: The authors have no financial interest to declare in relation to the content of this article.

lymphatic fluid drainage within the affected limb.²³⁻²⁶ LVB involves image-guided targeted supermicrosurgical anastomosis of obstructed lymphatic vessels to neighboring venules. The procedure is guided by near-infrared fluorescent lymphatic imaging (NIRFLI) following intradermal injection of indocyanine green (ICG) dye.²⁷ VLNT is indicated in patients with advanced lymphedema and involves microvascular anastomosis of functional lymph nodes from within regional lymph node basins into an extremity to restore physiological lymphatic function.^{23,24,28-30}

The chronic lymphedema phenotype is characterized by hypertrophy of fibroadipose soft tissues that can only be removed by minimally invasive suction-assisted lipectomy (SAL). In such cases, the reduction in limb volume is maintained by lifelong compression therapy.^{31,32} In the most advanced cases, debulking surgery by direct excision may be necessary.

Patients with lymphedema require a coordinated multidisciplinary complete program of care, which may need to be lifelong, optimally delivered by specialist lymphedema clinical programs within academic medical centers. There are, however, almost no formal resources to guide physicians on how to develop these programs.³³⁻³⁵ This article provides a concrete and actionable guide for building an academic lymphedema program, and reviewing lessons learned and adaptations made during the setting up a comprehensive clinical lymphedema program of excellence.

FUNDAMENTAL COMPONENTS FOR BUILDING A COMPREHENSIVE ACADEMIC LYMPHEDEMA PROGRAM OF EXCELLENCE

Successful modern academic medical centers recognize the need to establish multidisciplinary clinical programs of

excellence. Such programs develop coordinated care pathways, produce clinical outcomes research, and conduct clinical trials, with patient-centeredness at the core^{36,37} (Fig. 1).

Vision

Building a successful lymphedema program should begin with the final overall plan in mind with a comprehensive vision for the proposed program. Once the attributes considered important for success have been identified, program planning can take place within a multidisciplinary framework with engagement of all stakeholders and construction of specialist clinical teams.^{38,39}

Stakeholder Engagement

At MD Anderson Cancer Center, although already well-established in performing surgery for lymphedema, we made a commitment to embark on a mission to develop a formal lymphedema program of excellence. To achieve this, it was important to engage all stakeholders at an early stage to ensure clinical and infrastructural support to enable programmatic development. Establishing a truly multidisciplinary approach for coordination of patient care encouraged investment and participation of these stakeholders. In this way, our business plans could be constructed and resources could be appropriately allocated to support the growth of the initiative, in particular towards development of the infrastructure for patient evaluation and diagnosis, equipment for performing the surgery, and clinician and patient education, in addition to basic, clinical, and translational research.

Multidisciplinary Approach

Our leadership group recognizes the essential importance of a multidisciplinary approach and includes plastic surgery, breast surgical oncology, radiation oncology, breast

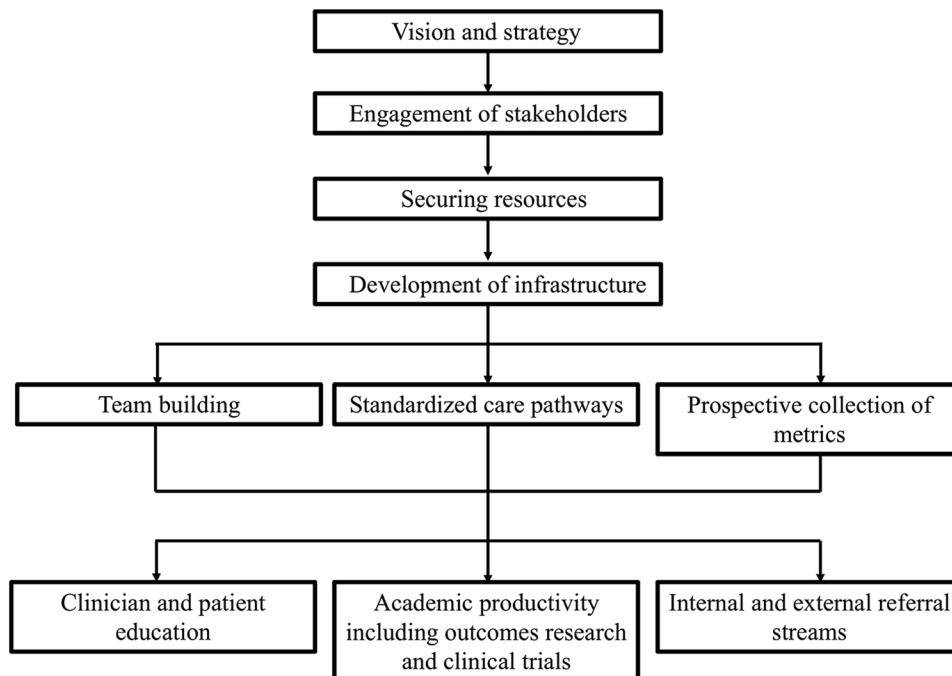


Fig. 1. Fundamental process for building a comprehensive academic lymphedema program of excellence.

medical oncology, and rehabilitative services and conducts regular meetings to engage individuals from all relevant disciplines to ensure their input and participation in the initiative that benefits all involved. This enables team members from the different academic departments to be allied, continuing the momentum gained during program activation. Involvement of other specialties, including melanoma, gynecological oncology, and urology, is also important.

Infrastructure

Critical to the success of the program has been the assembly of a robust and purpose-built infrastructure to achieve the predefined program goals. A modern innovative lymphedema program should include state-of-the-art clinical assessment tools and outpatient diagnostic/staging imaging modalities, as well as the full spectrum of surgical treatments available, with cutting-edge equipment for intraoperative imaging and for optimally performing surgeries to provide gold-standard care for patients. Prospective collection of metrics is performed in real-time using an information technology system (Research Electronic Data Capture purpose-built database).

Resources

Resources available to build clinical programs are often scarce at large academic medical centers, in particular for new initiatives that have not yet demonstrated financial results, and we initially constructed the program utilizing the existing infrastructure. The leadership group of the program made securing these resources from administration a high priority. We identified that the most critical of these resources is institutional support, including financial support, nursing clinical support, and technical support. Institutional support also needs to be made available for peer-to-peer review with insurance company medical directors if an appeal is required to obtain preapproval for surgical intervention.

Outcomes Metrics

It is important to have well-defined metrics of success that can be tracked and developed within an infrastructure that facilitates easy access to summary data reports, coordinated by a departmental program manager; these goals are reevaluated regularly to ensure continuous success of the program. These include metrics of efficiency, including the number of new patients, consults, second opinions, and follow-up appointments, the surgical procedures performed, and patient satisfaction surveys. It is important to have a baseline for these metrics before initiation of new components of the clinical program to demonstrate improved patient experience and satisfaction to stakeholders. The academic program should be focused on clinical outcomes research and the development of standardized lymphedema management algorithms stratified to disease stage was an important early step.

Referrals

Referring doctors need to be made aware of the program and how to refer their patients. Initial consults will be internal, so referring clinicians need to be engaged and educated to direct their patients to the program. The use of standardized referral criteria for the clinic schedulers

to use to screen referrals is important so that appropriate patients can be evaluated for surgical eligibility, and for patients not meeting these criteria guidance by the lymphedema-specialist clinical team is important to direct these patients to the appropriate service. Information technology can be used to facilitate internal referral processes and ensure that these patients reach the specialist teams.

Once the program is established, the goal should be to build a program that will receive outside referrals directly, depending on the specific demands of the healthcare market in the local geographic area. These new patients are an important source of revenue for the hospital: establishing care for lymphedema includes imaging, physical therapy, and lymphedema surgery, and it has been our experience that patients will transfer their oncological care to the hospital which they otherwise would not have done. The hospital needs to have well-established processes in place for accepting new patient referrals and for transferring their outside electronic medical records, and if these are not available then establishing them should be an early priority of a new lymphedema program. It is important to have new patient access coordinators that are trained to screen referrals with reference to standardized criteria and the lymphedema-specialist clinical teams should screen referrals on an individual if required and to direct patients to the correct providers should they not meet these criteria. Marketing can be used to generate outside referrals using universally applicable marketing strategies such as the use of media including local newspaper, television, and internet advertisements.

The key components required to build an academic lymphedema center are reviewed below (Table 1; Fig. 2):

Risk Reduction and Screening

Current National Comprehensive Cancer Network guidelines recommend monitoring for lymphedema as a part of the standard of care for patients with invasive breast cancer.⁴⁰ A lymphedema program should, therefore, include a mechanism for identification of patients at risk for developing lymphedema so that interventions can be directed to reduce their risk. Patients at risk should be included in a well-resourced screening program for detection and treatment of lymphedema at an early stage, when conservative therapy may prevent the development of persistent lymphedema.

At our center, we have a lymphedema screening program that includes pre- and postoperative measurements and evaluations performed at regular intervals with metrics recorded prospectively in the medical chart. Circumferential tape measurements are limited by high rates of observer error, and therefore modern programs like ours conduct screening by interlimb volumetric measurements using a perometer (optoelectric volumetry). Bioimpedance spectroscopy (BIS) is currently being investigated in an effort to diagnose preclinical or early clinical lymphedema.^{41,42} Patients who develop early lymphedema are then immediately identified to the treating team in order that non-surgical intervention can be instituted right away, followed by referral for surgical intervention if lymphedema persists despite 3–6 months of compliance with conservative treatment under the direction of a lymphedema-specialist PT.

Table 1. Key Components of an Academic Lymphedema Program

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- Prospective lymphedema surveillance/ screening program.
 - Outpatient clinical assessment tools including measurements of limb volume and extracellular fluid, patient-reported outcomes (PROs), and limb functional assessment tools, with prospective collection of data metrics.
 - Radiological diagnostic imaging.
 - Standardized treatment pathways.
 - Non-surgical lymphedema treatment by lymphedema-specialist PTs.
 - Range of consultative services for multidisciplinary patient management.
 - Equipment for performing image-guided lymphedema surgeries and for performing laparoscopic surgery.
 - Clinical outcomes research and participation in clinical trials.
 - Engagement in referring physician, lymphedema therapist, and patient education and workshops, as well as patient education leaflets and educational videos, information provided on a website, and media articles.
 - Defined referral criteria and pathways, engagement of the internal referral base with the referral process facilitated by information technology, and development of external referral base by advertising.
 - Regular evaluation of patient satisfaction with the service via patient surveys.
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Clinical Diagnosis and Staging

The accurate diagnosis of lymphedema and exclusion of other causes of swelling are essential. Clinicians must have expertise in the diagnosis of cancer-related, and non-cancer-related, primary and secondary lymphedema, as well as in systemic lymphatic disorders and congenital vascular anomalies including peditrics. It is important to recognize venous insufficiency and exclude venous thrombosis. Patients presenting with non-cancer-related lymphedema present a significant challenge to exclude lymphatic malformations and associated vascular disorders as well as other causes of limb swelling including lipedema. At MD Anderson, we work closely with a range of consultative services through a multidisciplinary referral framework for patients where a non-lymphedema cause of limb swelling is suspected, including vascular surgery, cardiology, orthopedics, rheumatology, among others.

The International Society of Lymphology staging scale is the most commonly used clinical staging system; physiological staging scales, including the MD Anderson Cancer Center ICG lymphedema,⁴³ and the dermal backflow, staging scales⁴⁴ using NIRFLI, and magnetic resonance lymphography (MRL),⁴⁵ may be more specific for stratifying patients for surgical intervention.

Assessment Tools

Tape measurements are well established and may be used to calculate the upper or lower extremity lymphedema indices or to derive volumes using truncated cone formulae; however, there is significant inter- and intra-rater variability. For limb volumetric measurements, the perometer is regarded as the current gold standard^{46,47}; however, the technique used needs to be standardized across the institution, clinical staff need to be fully trained, and the devices need to be regularly recalibrated to reduce variance between successive measurements—ideally to <1%. Horizontally configured perometers are specifically designed for upper extremity measurements, and upright perometers are used for measurement of lower extremity volumes; it may be possible to use these interchangeably with adaptations.⁴⁸ Although water displacement plethysmography is accurate, it is impractical in the clinical setting, and its use has largely been superseded by the perometer.

A growing body of evidence supports the use of BIS to measure the proportional difference in extracellular fluid between the affected and unaffected extremities, to

evaluate the outcomes of interventions,^{49,50} and for lymphedema screening.⁴¹ The combined use of the perometer and BIS provides complementary data with which to make clinical decisions.⁵¹ Volumetric computed tomography (CT) measurements and 3-dimensional (3D) stereophotogrammetry for limb volume measurement, and tonometry to measure soft tissue compliance, remain investigational.

It is important to include patient-reported outcomes in patient assessments to measure changes in psychosocial and physical morbidity in response to interventions. Validated tools for this purpose include the Lymphedema Life Impact Scale, Lymphedema Quality of Life Tool, Upper Limb Lymphedema 27, Lymphedema Quality of Life Inventory, Freiburg Life Quality Assessment for Lymphedema, and the Lymphoedema Functioning, Disability and Health Questionnaire for Lower Limb Lymphedema. Validated limb functional assessment tools, including the Disabilities of the Arm, Shoulder, and Hand Questionnaire (DASH/Quick-DASH), Lower Extremity Functional Scale, Upper Extremity Functional Index, and the Upper Limb Disability Questionnaire, provide complementary information regarding changes in physical disability in response to treatment.

Diagnostic Imaging

Imaging is essential for diagnosis and staging of lymphedema. The gold-standard investigation is radionuclide lymphoscintigraphy, which uses intradermal injection of technetium-99m-colloidal albumin with radioscintigraphic imaging of the transit of the radioisotope through the lymphatic system.⁵² This tool can also be used for reverse lymphatic mapping, where single-photon emission CT imaging can be used to provide 3D localizations of the sentinel lymph nodes in the superficial inguinal or axillary regions. Reverse lymphatic mapping reduces the risk of donor-extremity lymphedema after groin or lateral thoracic VLN flap harvest.⁵³

NIRFLI using intradermal ICG injection allows for detailed visualization of the lymphatic system for lymphedema diagnosis and staging, as well as for intraoperative guidance,^{43,54} and is increasingly being used in place of lymphoscintigraphy at high-volume lymphedema surgery centers. Several systems are available, including the PhotoDynamic Eye (Hamamatsu Inc., Japan), the SPY systems including the SPY Elite and Phi (Stryker Inc., USA), FLARE (Curadel LLC, USA), Fluobeam 800 (Fluoptics,

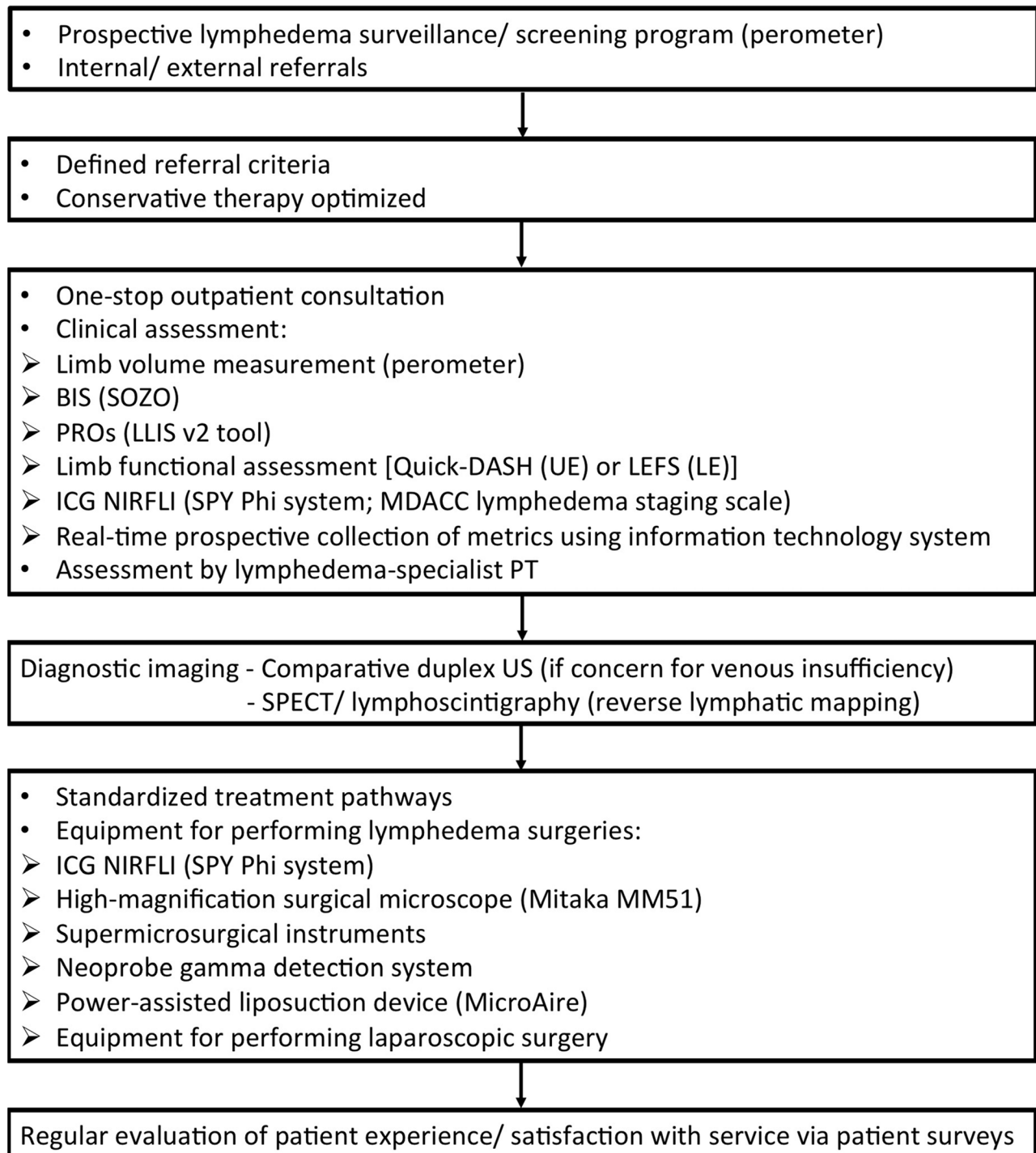


Fig. 2. MD Anderson cancer center lymphedema patient management pathway.

France), and the IC-Flow system (Diagnostic Green GmbH, Germany). These systems can be used in both the outpatient setting, as well as intraoperatively where they can be draped for sterility.

MRL involves the injection of gadolinium into the limb web spaces to image the lymphatic vessels and appraise the dermal backflow; subtraction venography can be used to discriminate between lymphatic vessels

and veins.⁴⁵ MRL can also differentiate between subcutaneous adipose tissue and fluid to help guide surgical management, and its use is increasing in popularity. This modality, however, is operator dependent and necessitates a radiologist with expertise in postprocessing and in evaluation of patients with lymphedema. Where concordant venous insufficiency is suspected or clinically diagnosed, venous investigations, including duplex

ultrasonography, CT or MR venography, or rarely direct contrast venography, may be indicated.

Non-surgical Treatment of Lymphedema

An essential requirement for a lymphedema center is patient access to conservative treatment, ideally delivered by skilled lymphedema-specialist PTs (Lymphology Association of North America-certified or equivalent). Many patients will present to a specialist lymphedema center with suboptimally managed lymphedema and require intensive conservative input with or without surgical intervention. Conservative therapy is essential for risk reduction and management of patients that develop lymphedema, including complete decongestive therapy, and skilled measurement for compression garments that may be required lifelong.¹⁰⁻¹² There is an opportunity for integrating the outpatient clinic with assessment using standardized measurements and evaluation with treatment by a lymphedema therapist. In this way, an outpatient assessment center with one-stop multidisciplinary clinics can be assembled with electronic collection of standardized outcomes metrics.

Consulting Services

A comprehensive range of consultative services is important for the combined management of complex patients with multiple comorbidities and etiologies. These may include psychiatric/ psychological services for depression and body image issues, pulmonary medicine, cardiology, gynecology, dermatology, urology, radiation oncology, nutrition (particularly for protein-losing enteropathy and lipedema patients, as well as for management of obesity), neurology, physical medicine and rehabilitation, orthopedics, rheumatology, vascular surgery, and diagnostic/ interventional radiology with capability for venoplasty/stenting for management of concomitant venous insufficiency, as well as lymphatic sclerotherapy and embolization.⁵⁵

Surgical Treatment of Lymphedema

The lymphedema surgical team should consist of clinicians with expertise in diagnosis of the range of primary and secondary lymphatic disorders and non-lymphatic etiologies of extremity swelling, including lipedema, to ensure that the patient is correctly diagnosed and appropriately managed. Surgeons treating lymphedema must also have a comprehensive set of surgical skills to treat the spectrum of lymphedema disorders^{23,24,28-30,56}; this includes LVB, VLNT, and debulking surgery using SAL or, rarely, direct excision. A range of VLNT options is necessary in the reconstructive armamentarium, as some donor sites may be unavailable owing to prior surgeries or patient preferences. Skilled laparoscopic capabilities within the surgical service are desirable, as laparoscopic omental flap harvest has distinct indications.²⁹

Performing LVB supermicrosurgery requires specialist technical skills and supermicrosurgical instruments. Advances in intraoperative imaging technology have greatly aided the performance of supermicrosurgery of lymphatic vessels of caliber <0.8 mm resulting in improved outcomes. NIRFLI is essential for visualizing and targeting these lymphatic vessels. The introduction of ultra-high

magnification surgical microscopes, in particular the Mitaka MM51 (Mitaka USA, Inc., Denver, CO, USA), has enabled high-resolution visualization of these lymphatic vessels for accurate microsurgical anastomosis, as well as intraoperative NIR fluorescence confirmation of patency. The Lymphatic Microsurgical Preventive Healing Approach (LYMPHA), in which lymphatic vessels severed at the time of lymphadenectomy are immediately bypassed into adjacent veins within the surgical field, has been shown in early studies to reduce the risk of subsequent lymphedema development; this technique is currently undergoing further study.^{57,58} Lymphedema surgery programs should offer immediate lymphatic reconstruction under the auspices of a clinical trial.

For VLNT, a neoprobe gamma detection system (Devicor Medical Products, Inc., Leica Biosystems, Nussloch, Germany) may be required if reverse lymphatic mapping using radioisotope is employed. For SAL debulking procedures, the subcutaneous tissues are typically fibrous and power-assisted systems are typically needed to extract this tissue.

Training

Centers specializing in lymphedema treatment should engage in teaching trainees not only lymphedema surgical techniques, but also the management of lymphedema. It is also valuable to teach trainees the fundamentals of starting a lymphedema treatment program so that they can develop these at other academic centers.

Research

A comprehensive lymphedema program should ensure that complete datasets are collected in a standardized fashion so that they can be used for outcomes research. Prospective electronic real-time collection of clinical outcomes data using an information technology system facilitates outcomes research. Coordination of these follow-up appointments with other oncological appointments at the hospital improves compliance. Such programs should also aim to include patients in prospective clinical studies and clinical trials comparing the effectiveness of various interventions. Basic science studies of the mechanisms of lymphedema and possible pharmacological treatments are also desirable to enable translational research and to advance the science of lymphedema. Anatomical research can be greatly aided by access to a cadaver laboratory with capabilities to perform injection and radiographic studies.

Education

A comprehensive lymphedema program should be actively engaged in educating referring physicians, lymphedema therapists, and patients. It is particularly crucial that all referring services are well educated regarding the services that are provided by the lymphedema center, the referral criteria, and the referral pathway; this will increase the proportion of referred patients that are candidates for surgery.

Educational opportunities should be provided at local multidisciplinary events and workshops for both physicians and lymphedema therapists, and by local dissemination of

educational literature. Patient education is also essential and should be outward-facing; patient educational initiatives include leaflets and videos, informational websites, use of social media, and media articles.

Patient Referrals

Clinicians must be made aware of the program and how to refer their patients. The internal referral base is established by engaging the institution's referring clinicians to direct their patients to the program; this can be achieved by using educational strategies, including presentations and educational events. The strategies for developing the external referral base will depend on the local healthcare market conditions, and may include advertisements in local newspapers, on television, and on the internet. The use of standardized referral criteria increases the proportion of patients seen at clinic that are candidates for surgical intervention, enabling resources to be directed to those that can benefit most from them.

Service Excellence

Program leaders should concentrate on taking a patient-centered approach that demonstrates a commitment to service excellence by focusing on the patient experience of care.^{36,37,59,60} Patient-reported outcomes should be collected routinely, and patients should have an opportunity to convey their experience and satisfaction with the program's service via periodic or ongoing surveys, as well as recommendations for improving the service.

CONCLUSIONS

Lessons learned during the building of our academic lymphedema program may benefit others who are embarking on this mission and provide a structured roadmap. Development of a successful comprehensive academic clinical lymphedema program of excellence requires thoughtful vision, careful team building, assembly of infrastructure, establishment of coordinated care pathways, prospective collection of metrics for quality control and evaluation of outcomes, academic research productivity, and strategies for attracting internal and external referrals. Adoption of bundled payment or value-based purchasing reimbursement models is anticipated to financially incentivize the building of such multidisciplinary academic programs and the financial and healthcare benefits of these surgeries are an area of ongoing investigation.^{8,62}

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