

Management of Primary and Secondary Lymphedema: Analysis of 400 Referrals to a Center

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Background: Lymphedema is the progressive swelling of tissue due to inadequate lymphatic function. Although lymphedema is a specific condition, patients with a large extremity are often labeled as having “lymphedema”, regardless of the underlying cause. The purpose of this study was to characterize referrals to a center to determine if lymphedema should be managed by specialists.

Methods: Patients treated in our Lymphedema Program between 2009 and 2016 were reviewed. Diagnosis was determined based on history, physical examination, photographs, and imaging studies. Lymphedema type (primary, secondary), location of swelling, age, gender, previous management, accuracy of referral diagnosis and the geographic origin were documented.

Results: Four hundred patients were referred with a diagnosis of “lymphedema”; 70% were female and 30% were children. Lymphedema was confirmed in 73% of the cohort: primary (56%) and secondary (44%). Twenty-seven percent of patients labeled with “lymphedema” had another condition. Before referral, only 4% of the cohort underwent lymphoscintigraphy (the gold standard diagnostic test for lymphedema), whereas 31% of patients with lymphedema received nondiagnostic tests for lymphedema. Eight percent were given a diuretic which does not improve the condition. One-third of patients resided outside of our local referral area. The average time between onset of lymphedema and referral to our Lymphedema Program was 10 years (range, <1–62 years).

Conclusions: Patients presenting to a center with “lymphedema” often have another condition, and may be suboptimally managed prior to their referral. Patients with suspected lymphedema should be referred to specialists focused on this disease.