

*LYMPHSPARATION***HOME VOLUMETRY FORETELLS A NEW ERA
OF SELF-MANAGEMENT FOR PATIENTS WITH LYMPHEDEMA
AFTER BREAST CANCER**

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ABSTRACT

We designed a device for quick and accurate measurement of arm volume at home. The device is non-commercial, and plans for construction and use are widely available. A single subject with arm lymphedema used the volumeter at home for more than one year and learned to better self-manage her condition. She discovered that symptoms commonly associated with worsening lymphedema (painful, heavy arm) are often unrelated to arm volume, transient, and therefore require no treatment. She was able to customize treatment including measuring the impact of various treatments and devices on arm volume. In the previous summer, the subject experienced worsening edema, which required 5 weeks of intensive treatment. During the summer of the study, the subject found that as temperatures increased the decrease in arm volume she normally experienced at night reversed, resulting in a slow and gradual increase in edema. She then tested several therapeutic interventions and devices and found that wearing a Class 1 sleeve at night during the summer months was the most effective intervention to maintain her arm volume. We predict that home volumetry will be useful

for the management of lymphedema and particularly allows patients an increased ability to manage their symptoms.

Keywords: lymphedema, evidence-based self-management, home volumeter, breast cancer

To observe and follow arm volume, patients are usually instructed to measure circumference of the arm at specific points using a measuring tape (1). Patients find it is technically difficult to measure with one hand to ensure consistent tape tension. Despite its widespread use, some reports find that geometric extrapolation of girth measurements to arrive at arm volume is too imprecise to be of clinical usefulness to assess therapeutic interventions (2). There are other high-tech devices, but these are too expensive and impractical for home use (3-5).

The gold standard for arm volume measurement is the 2000 year-old water displacement principle discovered by Archimedes. The standard water displacement volumeter is too large, fragile, cumbersome, and expensive for home use, and patients do not have routine access to volumeters in clinics (outside research settings), which may be fortunate considering the risk of transmission of bacterial and fungal skin infections.

We designed an arm volumeter specifically for quick and accurate measurement of arm volume at home, and our validation study (6) showed that it is more accurate and precise ($R^2=0.9974$) than the standard volumeter used worldwide (Sammons Preston Rolyan, a Patterson Company, 270 Remington Blvd., Suite C, Bolingbrook, IL 60440-3593). Whereas the standard volumeter is expensive, fragile (acrylic), and prone to leaks, our volumeter is inexpensive, simple, assembled from readily available plumbing materials, leakproof and virtually indestructible. We have no underlying commercial interests and detailed, illustrated instructions for construction and use are freely available in print and on the web (6).

Although many physicians and therapists have written to us indicating their interest in having our volumeter constructed for their lymphedema clinics, to our surprise, there was widespread reluctance to transferring responsibility of arm measurement to the patient at home. The purpose of this communication is to address this widespread skepticism since measurement at home was the main reason for our invention. Instead of presenting a theoretical argument about the benefits of home volumetry, we present here “patient zero,” the first patient with lymphedema after breast cancer in the medical literature to serially record arm volumes using a home volumeter.

The subject, who was provided the prototype volumeter used in our study, was a 49 year old very active, fully mobile, intelligent, motivated, and resourceful accountant. She had developed mild to moderate non-fibrotic lymphedema 2 years after a mastectomy and irradiation for the treatment of breast cancer but otherwise in remission, and was wearing a Class 2 compression garment during the day. The patient signed an informed consent and the study was approved by the ethics committee of Maisonneuve Hospital. She recorded objective volume measurements which allowed her to practice evidence-based self-management.

Experimental Procedures and Results

The procedure (including 3 consecutive measurements each time with a standard deviation of 5 ml) took 15 minutes and provided immediate, precise feedback, an improvement over one-handed tape measurements and geometric calculation for determination of arm volume. The volumeter has survived a year of rough handling with no leaks or breakage and was compact enough to be stored in the bathroom.

The subject measured arm volume daily for 3 months and 3 times a week thereafter. At first, she tended to attribute significance to small variations in volume until she understood that she should think in terms of range of volume instead of absolute volume. She observed that her arm volume fluctuates naturally by about 80 ml (1740 ml to 1820 ml). Consequently, she realized that all therapeutic interventions started within her “normal” range were futile. Only when her arm volume exceeded her upper limit could a volume reduction be achieved. The subject also discovered that symptoms commonly associated with an increased arm volume such as a painful and heavy arm were uncorrelated for her. Volumetry provided either objective confirmation (in ml) of worsening lymphedema or, in most cases, reassurance that many symptoms were unrelated to volume, and could be considered transient.

The subject evaluated a multitude of therapeutic interventions and devices such as rest with elevation, exercise, various breathing exercises, manual lymphatic drainage, compression bandaging, and compression devices, to decide which ones were effective in her case and to what extent (in ml). She found that none of the expensive and bulky nighttime compression devices that she had purchased and used on a regular basis had any significant impact on her arm volume. By systematic testing, she discovered that the single most effective intervention to reduce her arm volume when it exceeded her upper

limit was to wear a Class 1 compression sleeve at night, which was probably the least uncomfortable or intrusive of all therapeutic interventions.

Preclinical Intervention – A New Facet of Self-Management

Factors such as air travel and hot weather and others can be aggravating to patients with lymphedema. The most significant aggravating factor that our subject identified is summer heat. During the previous summer, she experienced a large increase in arm volume which required 5 weeks of daily manual lymphatic drainage and compression bandaging to control the swelling. In the study year, she measured arm volume morning and evening as summer approached and found that the normal pattern of night time decrease in arm volume reversed as weather became warmer. Each night, arm volume would irreversibly be increased by a small increment of approximately 20 ml (which explains how an imperceptible increase can accumulate over time unbeknown to the patient). She started wearing a Class 1 sleeve for treatment at night, and her arm volume remained within her normal range despite a hot summer.

Potential Drawbacks

Easy access to arm volume measurements carries the risk of a psychological syndrome which we shall call “volumania” in patients with obsessive-compulsive personality traits. Perfectionists may become fixated on minor volume changes that are within the range of normal fluctuations as opposed to a real deterioration. In addition, the results from this single subject may not be replicated in larger populations or in patients with other presentations of lymphedema.

CONCLUSION

Measurement of arm volume at home

may foretell a new era in patient-customized evidence-based lymphedema management. Armed with a home volumeter, patients can evaluate, criticize, refute or accept interventions and devices based on hard evidence rather than tradition. This may allow innovations in treatment to come from groups of motivated and industrious patients who study their volumetric records in addition to those from the lymphedema “medical-industrial complex.”

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[In addition, detailed, illustrated instructions for construction and use of the volumeter (at no charge) may be obtained from the author at jlette@lette.com.]

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