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Functional outcomes measurement in the absence of disability: The lymphedema example

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Background: Treatment of lymphedema falls mainly into the scope of practice of therapists. Unfortunately the measurement tools employed by therapists over the years have been developed to measure functional disability, and the goal of lymphedema treatment is to treat it in an early enough stage to prevent disability. Furthermore there are currently few lymphedema measures or outcome tools to measure midline lymphedema (breast, torso, genital, head and neck).

Methods: We review new devices being evaluated that may be suitable for objective measurement of non-extremity lymphedema, such as lymphedema of the breast and chest, torso, head and neck and abdomen. We review status of protocols using skin thickness measurements by ultrasound and MRI, skin tissue water content using bio-impedance and dielectric constant instruments, and elasticity measurements. We discuss new questionnaires that are being specifically designed for the subjective measurement of lymphedema in accordance with the ICF framework. These new instruments promise to be more sensitive to changes in lymphatic system function and severity than the currently utilized general measures of function and current specific measurement instruments.

Results: We identify a number of promising new objective measurement devices for measurement of extremity and midline lymphedema severity, and we list promising new subjective measurement instruments with high sensitivity to changes in lymphedema severity even before it becomes disabling.

Conclusions: With the inexorable advance of “pay for performance” replacing “pay for service” reimbursement it is of vital importance that new functional outcome measurement instruments be developed to support reimbursement for treatment of lymphedema.

Biography

Robert Weiss is a retired aerospace systems engineer with a Master of Science degree from the University of California at Los Angeles. He has completed 80 hours of Dr. Vodder lymphedema therapy training, and is a graduate of the NLN LSAP Program, NBCC Project LEAD and Quality Care LEAD. He has co-authored a systematic review of manual therapy for breast cancer-related lymphedema for the Cochrane Collaboration. He is a member of the ALFP Steering Committee, is a PCORI Merit Reviewer and lectures at lymphedema conferences on incidence and prevalence of lymphedema, breast lymphedema, cost-efficacy of lymphedema treatment, and lymphedema insurance, reimbursement and legislation.

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