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MU Researchers Collaborate to Develop Standard of Care for Breast Cancer Survivors with Lymphedema By Nancy McMullen

COLUMBIA, Mo. – Lymphedema, a chronic swelling condition that can appear after breast cancer surgery, is a risk for 1.3 million breast cancer survivors. Although lymphedema can cause lifelong swelling in the arms, back, neck and chest, there is no national standard of diagnosis or care. Now, University of Missouri researchers are leading the [American Lymphedema Framework Project](#) (ALFP), a national, multi-disciplinary collaboration to develop comprehensive guidelines for the assessment, treatment, and management of lymphedema.

“We can’t cure lymphedema today – we can only manage it,” said [Jane Armer, MU nursing professor](#) and director of the project at the [MU Ellis Fischel Cancer Center](#). “Lymphedema is a complex, chronic condition. Currently, there are inconsistent approaches to care for lymphedema, and often the most common form of self-management is to not treat it at all.”

The ALFP, established in 2008, has two main goals: establish a best practices document with evidence-based lymphedema treatment guidelines for health practitioners, and create a minimum data set of all available lymphedema research and clinical data. The ALFP researchers plan to publish the best practices document in 2011.

“Part of why there isn’t a standard of care is the lack of reliance on current evidence by health practitioners and third party payers, which in turn causes problems with reimbursement from health insurance companies. Many people with lymphedema have to pay out-of-pocket for care,” Armer said. “There isn’t a clear, national consensus for how to diagnose lymphedema and when to start treating it. The ALFP collaborators aim to document a standard of care reflecting a consensus on best practices that will help solve these problems.”

Researchers, including those at MU, have found that the most effective method of care for lymphedema is complete decongestive physiotherapy, in which therapists use specialized lymphatic massage techniques to reduce protein-rich fluid buildup. Bandages and compression garments also help to reduce swelling.

One of Armer’s innovations at MU is measuring patients’ arms with a perometer, a machine that was first used to fit garments for swollen limbs. First implemented in a research setting at MU, the machine has a large optoelectric frame that glides over a patient’s arm, scans its image and records an estimated limb volume reading. Perometer measurement is as, or more, accurate than several previous methods to measure arm circumference and volume. The machine is now used in about 20 sites across the country.

Highlights of [MU Sinclair School of Nursing](#) research from the past 10 years reveal that there is a 40 percent higher risk of developing lymphedema in women with a body mass index (BMI) classified as overweight or obese compared to normal-weight women. The researchers also found that younger patients may have less occurrence of the condition but tend to report more symptoms, which could be a result of psychological and aging-related factors.

“In addition to our previous findings, we’re currently studying whether there are any genetic factors that increase the risk of lymphedema,” Armer said. “A pilot study now underway and a proposed multi-site research study will look at the possibility of genetic predisposition for secondary lymphedema. The results could be applied to cancer treatment in which surgery and radiation affect the lymphatic system.”

In recognition of the leadership in lymphedema research at MU, the ALFP is housed at the MU Ellis Fischel Cancer Center. Armer’s research is funded by the National Institutes of Health and is published in several journals, including the *Journal of Lymphoedema*; *Lymphology*; *Lymphatic Research and Biology*; and the *Journal of Cancer Survivorship*, and presented at conferences throughout the world. The activities of the ALFP have been funded by industry partnerships and grants from the American Cancer Society through The Longaberger Company, a direct-selling company offering home products, and the Longaberger Horizon of Hope Campaign, which provided a grant for breast cancer research and education.