

Study identifies patient strategies for managing symptoms of lymphedema

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An estimated 2 million women in the United States are at risk of developing lymphedema, a condition that involves the chronic and abnormal swelling of the arm, chest, neck and/or back, as a complication of breast cancer treatment. While physicians will recommend proven techniques to manage the swelling, a University of Missouri researcher has found that patients often won't follow the recommendations, or they will use alternative treatments and not discuss them with their doctors.

"Lymphedema has a profound impact on health and well-being, but often goes undiagnosed and untreated by physicians and patients," said Jane Armer, professor in the Sinclair School of Nursing and director of nursing research at the Ellis Fischel Cancer Center. "Understanding the ways that people self-manage the chronic symptoms of lymphedema is essential to facilitate an improvement in the use of treatments and the quality of life of these people."

Armer surveyed breast cancer survivors with lymphedema about their practices for managing symptoms, including swelling and heaviness. She found the most common strategy was to not treat the symptom. For 12 out of 14 symptoms, patients reported taking no action 29 percent to 65 percent of the time. This finding is consistent with Armer's conclusions from a previous study.

"Considering the entire lymphedema population (not just breast cancer survivors), the percentage of patients who treat their symptoms is probably even lower," Armer said. "Data have shown that breast cancer survivors are more proactive in seeking information for self-care, and they are more likely to follow a daily self-care plan for lymphedema than those who developed lymphedema for a different reason."

Armer found that patients who choose to treat their symptoms use a variety of techniques, which can

be divided into three main groups. The first group includes recommended management techniques, non-pharmaceutical strategies typically recommended by physicians, including manual lymphatic drainage, compression garments and elevation. Patients use these techniques most often, or 47 percent of the time. The second group was pharmaceutical treatments including the use of medications both prescription (antibiotics) and over-the-counter (pain medication and cortisone cream). The final group was lay symptom management techniques, strategies not necessarily recommended by health care professionals but common sense, folk, complementary or alternative methods.

According to Armer, patients increasingly are using lay therapies, but less than 40 percent report discussing their use of complementary therapies with a doctor. Previous research has found these unconventional therapies are generally not taught at medical schools or are unavailable at most hospitals.

"While lay symptom management is undoubtedly an important form of health care, the discrepancy between the use of self-care treatments and doctor-recommended treatments for lymphedema must be addressed," Armer said. "It's important for health care professionals to recognize the scope and diversity of practices that breast cancer survivors choose when managing their symptoms. Continued research of this issue can help develop effective management techniques to be incorporated into standards of practice for physicians and patients."

The Lymphedema Research Project at Ellis Fischel and Sinclair School of Nursing provides research opportunities for breast cancer survivors to participate in oncology nursing research. The studies are funded by the Lance Armstrong Foundation and the National Institutes of Health. MU researchers maintain a database of participants for future studies; interested participants for breast

cancer and/or lymphedema research may submit their contact information and will be contacted if they meet the criteria for current or new studies. Friends, family members and co-workers who have not had breast cancer or lymphedema also may enroll for studies that require matched control participants.

"We are experiencing great success by connecting participants to studies through our database. It gives people an opportunity to contribute to breast cancer research and allows our research efforts to continue," Armer said. "A critical next step in lymphedema research is the rigorous evaluation of the effectiveness of self-management techniques."

The study, "Self-Reported Management of Breast Cancer-Related Lymphoedema," was published in the Journal of Lymphoedema.

Source: University of Missouri-Columbia

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