

New registry will track lymphedema among breast cancer patients

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(Medical Xpress) -- More and more woman are surviving breast cancer, but lifesaving surgical and radiation therapies can cause a grave side effect: an incurable chronic condition called lymphedema that involves swelling of the arms and often debilitating pain and discomfort. While this disorder frequently has been ignored, misdiagnosed and untreated in breast-cancer survivors, that's beginning to change.

In an effort to find better treatment and preventive strategies for [lymphedema](#), researchers at the Stanford University School of Medicine are launching a patient registry to study breast-cancer-related lymphedema. The information and records of [breast cancer survivors](#) gathered in the registry will be used in a study to determine whether early diagnosis of lymphedema can help treat and, possibly, prevent it.

“There is early evidence to suggest that prompt diagnosis may reduce the severity or eliminate this problem,” said Stanley Rockson, MD, the Allan and Tina Neill Professor of Lymphatic Research and Medicine, the lead investigator of the study. “If you take a wait-and-see treatment approach, by the time the lymphedema becomes noticeable, it can be quite advanced. Caught earlier, it may be more manageable, or even reversible.

“Oncologists and surgeons are becoming more aware of the need, and there are new technologies that help with early diagnosis.”

A leading expert in lymphatic diseases, Rockson, who directs the Center

for Lymphatic and Venous Disorders at Stanford, helped establish the first patient registry and tissue bank for patients with lymphatic disorders in 2009.

For this new study, Stanford researchers hope to recruit an estimated 1,000 breast-cancer survivors for the Stanford National Breast Cancer Lymphedema Registry.

“Members of the American Society of Breast Surgeons will have the opportunity to collaborate in this project,” according to a statement from the society. “Member surgeons can choose to help Stanford in the identification of patients to be enrolled in the registry and will facilitate participation through the society's web-based quality reporting initiative.”

Participants will periodically update information about any symptoms, test results or treatments in 15-minute online sessions. They'll give approval for their surgeons to provide their treatment information to the registry. Identifying information will be removed.

Currently, there is no cure for lymphedema, a disorder that arises in 15-60 percent of [breast cancer](#) survivors. A lifelong problem of disrupted lymph circulation characterized by fatigue, limb swelling and loss of the integrity of the skin, the condition's severity can range from mild discomfort to disabling disfigurement, pain and loss of function.

When lymph circulation is delayed or interrupted, swelling and inflammation can result from a traffic jam of lymph that builds up in the limbs. There are multiple sources of blockages but often they are caused by tumor removal surgery, radiation treatment or lymph node biopsy. The only available treatments are physical therapies, including skin massage, drainage and pressure bandages, though the long-term effectiveness of these therapies has not been carefully studied.

More information: Patients interested in enrolling can log into the Stanford National Breast Cancer Lymphedema Registry website at: breastcancer-lymphedema.stanford.edu

Provided by Stanford University Medical Center

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