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Researchers conduct study with innovative tools to help early identification and treatment of lymphedema

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Each year, about 1.38 million women worldwide are diagnosed with breast cancer. Advances in diagnosis and treatment have facilitated a 90 percent, five-year survival rate, among those treated. Given the increased rate and length of survival following breast cancer, more and more survivors are facing a life-time risk of developing breast cancer-related lymphedema; one of the most distressing and feared late onset effects.

Lymphedema, characterized by the abnormal swelling of one or more limbs, is most often the result of an obstruction or disruption of the lymphatic system over the course of the cancer treatment. Lymphedema usually manifests after a latent period of one, to five, or even as much as twenty years, after treatment. Consequently, lymphedema remains a major health problem, affecting 40% of the 3.1 million breast cancer survivors in the United States and exerting a tremendously negative impact on survivors' quality of life.

"Similar to risk reduction and management of other chronic diseases (e.g., diabetes or heart disease), proactive and preventive education on signs and symptoms of lymphedema and risk reduction activities is essential for early identification and treatment of lymphedema," says New York University Rory Meyers College of Nursing (NYU Meyers) researcher and professor, Mei R. Fu, PhD, RN, FAAN.

Researchers note, some 40 percent of breast cancer survivors never even

receive information about lymphedema from their physicians, even though they are all potentially at risk. Research has shown that at least half of all survivors without a diagnosis of lymphedema have reported experiencing at least one lymphedema associated symptom, a cardinal sign of an early stage diagnosis and, "a key time to begin treatment before fluid build-up can be detected," notes Dr. Fu. To counteract the paucity of follow-up information and to augment early diagnosis and interventional treatment, Dr. Fu, Dr. Yao Wang (Professor of Computer Engineering at NYU Tandon), Dr. Deborah M. Axelrod and Dr. Amber Guth (Professor of Surgery, NYU Langone Medical Center), and fellow NYU researchers developed "The Optimal Lymph-Flow" (TOLF), an electronic teaching system to assist breast cancer survivors in-home post-operative self-care.

They report their findings in a new study, published in *mHealth* (July 2016), "mHealth self-care interventions: Managing symptoms following breast cancer treatment." The study describes TOLF's research-based skills for the feasibility of developing innovative, safe, and easily-integrated-into-daily-routine self-care strategies to mitigate the onset of lymphedema.

TOLF consists of three electronic tools, accessible via any smartphone, tablet, or laptop, to assist in self-assessment, early diagnosis, and pain and symptom management. These three tools collect demographic and clinical information related to the survivor's treatment history, daily self-inventories of occurrence and distress of symptoms, and avatar videos of at-home lymphatic exercises for those who experience any of the 22 lymphedema related symptoms even if they do not have a diagnosis of lymphedema , to provide management and relief of pain and symptoms.

"In usability testing of 30 patients, 90% of participants reported no problems of using the system, the other 10% reported only minor cosmetic issues; 93% reported total agreement in ease of use," said Dr.

Wang.This NYU research team conducted a 12-week study of 20 survivors over the age of 21, who experienced pain and other lymphedema related symptoms. All the participants reported TOLF self-care intervention relieved pain and other symptoms and reduced the various negative aspects and impacts of having lymphedema symptoms.

"Easy access to high quality health information for lymphedema symptom management is essential for patient-centered care to achieve health equity. Participants loved the fact that they as patients can access TOLF at anytime and anywhere and learn about lymphedema, symptoms, and self-care strategies at their own pace," said Dr. Fu.

Dr. Fu does note that the majority of participants were of relatively high educational levels and familiar with internet use, so further testing will need to be done with survivors of different characteristics.

Dr. Fu and others hope that the integration of TOLF into survivor's daily lives will increase diagnosis and treatment before fluid build-up begins and significantly reduce the pain and negative impacts of lymphedema symptoms.

More information: Mei R. Fu et al. mHealth self-care interventions: managing symptoms following breast cancer treatment, *mHealth* (2016). DOI: 10.21037/mhealth.2016.07.03

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