Breast Cancer Patients’ Fear of Developing Lymphedema Far Exceeds Risk

Women who have had the lymph nodes under their arm surgically removed during breast cancer treatment are warned to avoid certain practices that can cause lymphedema—a condition that causes chronic, painless swelling in the arm. Now, a new study published in the March issue of the Journal of the American College of Surgeons suggests that the vast majority of women who undergo breast cancer operations worry about developing this complication and that this fear far exceeds their actual risk of getting lymphedema. In fact, most women adopt four to five commonly recommended measures to prevent this incurable condition despite little data supporting the efficacy of these precautionary behaviors.

During breast cancer treatment, women are advised to take certain preventive steps to reduce their chance of developing lymphedema. These preventive measures include vigilant skin care to avoid injury (avoidance of needle punctures or blood draws), not getting one’s blood pressure taken in the affected arm, frequent use of compression garments, and various other practices. The truth is that clinicians don’t really know if any of these precautionary measures change the outcomes for these women.

“Clinicians don’t really know what causes lymphedema, and there is an overall lack of data supporting or refuting these risk-reducing practices,” said lead study author Sarah McLaughlin, MD, FACS, assistant professor of surgery at the Mayo Clinic in Jacksonville, FL. “And because women worry about that disfiguring process, they adopt practices that are basically grounded in myth, not fact.”

About 90 percent of women who will develop lymphedema do so within three years of breast cancer treatment. It occurs in about 20 percent of women who undergo axillary lymph node dissection (ALND)—a procedure in which 10–20 lymph nodes (on average) in the armpit are removed and checked for cancer cells. It also develops in about 5 percent of women who undergo sentinel lymph node biopsy (SLNB)—a less extensive procedure in which only a few lymph nodes closest to the breast are taken out and analyzed.

To document the lymphedema rate, patient worry, and risk-reduction behaviors in women undergoing breast cancer surgery, researchers at the Mayo Clinic in Florida followed 120 women, ages 52-68, for 12 months. Of those women, 53 underwent ALND and 67 had SLNB. The same two clinicians saw all patients postoperatively at one-, six-, and 12-month intervals. During these visits, the women completed questionnaires about their lymphedema risk-reduction behaviors, and assessments of their fear and worry about developing the condition.

Researchers found that 75 percent of women who had ALND, and 52 percent of women who had SLNB, worried about getting lymphedema. While lymph node

removal can increase the chance of developing this complication, the study results showed that only 19 percent of those who had ALND actually developed lymphedema, and only 3 percent of those who underwent SLNB got it. The study also showed that at 12 months, the extent of axillary surgery (the number of nodes taken out in the armpit) was the only significant risk for developing lymphedema. Age, weight, type of breast operation (breast-conserving or mastectomy), or radiation were not linked to an increase in lymphedema.

What's more, researchers found that the majority of women adopted as many as five precautionary behaviors as early as six months after breast cancer operations and maintained these behaviors long term despite their actual risk—meaning they undertook these measures regardless of whether they had undergone ALND or SLNB and their course of treatment (radiation and adjuvant chemotherapy).

The investigators say that future research should be aimed at better predicting which women will develop lymphedema, thus allowing for targeted prevention and intervention strategies and individualized plans for risk-reducing behaviors for each woman during and after her breast cancer treatment.

"This is the first step to quantify the problem. The aim is to educate not just patients but providers about what we really need to do, which is to better stratify patients in terms of what their true risk really is," Dr. McLaughlin said. "The goal is to be able to tell the average woman, 'Listen, your risk is low so you don't need to do these other things, and you can go about your life and be active and not worry to such a great extent that you are going to suffer this complication.' The goal is to alleviate much of the anxiety that women carry," Dr. McLaughlin said.

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