Debunking Lymphedema Risk Reduction Behaviors: Not So Fast

This week I opened up a New England Journal of Medicine Journal Watch update and read: “Study Debunks Conventional Guidance in Lymphedema Prevention.”

This is a newsletter from a prestigious medical journal, reporting on a study from a Harvard affiliated hospital. It came from a very trustworthy source, could this practice changing information be trusted?

Well, I got the article and the editorial and I read every line, and found that the actual article didn’t prove that traumatizing an at risk arm with medical interventions was safe, and the editorial, unfortunately took a modest study and trumpeted that only two things cause lymphedema—obesity and infection—and taking blood pressures in the at risk arm should be the new normal. And then, the New England Journal took the editorial’s headline and dispersed it.

So, if you don’t take the time to get the article, or don’t have access to it, you could be under the belief that new studies show that traumatizing an at risk arm is completely safe. But that would be wrong.

On March 1, 2016 an article was published in the Journal of Clinical Oncology (1), from a group at Mass General who had followed over 600 women, taking perometry arm measurements at least 3 times, and they asked them if they’d had blood draws, injections, IV’s or blood pressure measurements in their at risk arm. Any woman who had flown on a plane and used compression was excluded from the study.

The Mass General study measured women with perometry, a laser measurement that is very good at measuring the volume of an arm from the wrist up. They defined a significant change as a 10% increase. They were careful NOT to say that women developed lymphedema, as there is no universal definition of lymphedema, but rather limited their findings to “increased swelling.”

Most women avoided medical trauma to their arms: only 2.1% had an injection and 8.5% had a blood draw.

The study concluded: “Although we cannot affirmatively state that risk-reduction practices have no effect on arm swelling, we hope to generate evidence that brings reasonable doubt to burdensome guidelines and encourage further investigation into nonprecautionary behaviors and the risk of lymphedema. “

So, they didn’t find that in the small numbers of their patients who recalled having medical procedures in their arms or flew without compression that they had a large increase in swelling of the part of their arms they could measure. But they couldn’t definitively say it was safe.
The limitations of the study were that only a small percentage of the women recalled that they were exposed to risk, that it was self-reported, and that the perometer can’t measure swelling in hands, breasts, trunks—the entire quadrant that is at risk in breast cancer.

Also, volume measurement, used alone isn’t that sensitive for diagnosing lymphedema. Another study found that in 50 women, 5% measured a 10% increase but when they were clinically evaluated, an additional 31% had arm lymphedema and 8% had hand lymphedema. (4)

In the same Journal of Clinical Oncology, the article was reviewed (2), and these reviewers came to the conclusion that only obesity and infection are risk factors for lymphedema—ignoring all of the other risk factors such as radiation, number of nodes removed, genetic predisposition, chemotherapy and aging and stated: “As for other preventative behaviors, patients should be informed that there are not enough data to justify recommending strict adherence to avoiding skin punctures, blood pressure measurements, or use of compressive garments for air travel.”

This editorial looked at an older article for determining if women should wear compression for air travel (3). It’s not a great article. And even its author, who felt women shouldn’t wear garments on flights less than 4.5 hours, concluded: “this is not to say that there is no risk, or no women at risk, or that swelling never occurs.”

So, where does this leave the person at risk for lymphedema and their healthcare providers?

If their providers just read the one line synopsis, they might conclude that reputable journals have proved that no risk reduction behaviors are needed for lymphedema.

And that puts women in a very difficult place, as they may ask not to have blood pressure measurements—especially the high pressure automatic cuffs—or IV’s, or blood draws in their at risk arm and be met with resistance.

I asked Jane Armer, a noted researcher and head of the American Lymphedema Framework Project to review these articles, and she felt that as a clinician and researcher, they don’t change her recommendations. Avoid unnecessary trauma to an at risk arm.

The most controversial issue is the use of compression garments while flying in a person who has not developed lymphedema. The consensus is that at risk women should be carefully evaluated and discuss this with a knowledgeable physician, and if they chose to wear compression on a flight, to have it well fitted and to compress the hand as well as the arm.

Lymphedema is incurable. Why risk it? Even a low risk procedure will be 100% if it triggers lymphedema.
The movement to debunk lymphedema risk reduction behaviors comes from a desire to unburden women. Yet having lymphedema is a tremendous burden.

RISK REDUCTION BEHAVIORS HAVE NOT BEEN DEBUNKED. BUT YOUR HEALTHCARE PROVIDER MIGHT NOT HAVE READ THE ENTIRE ARTICLE, SO YOU MAY HAVE TO ADVOCATE FOR YOURSELF, OR INFORM THEM.

4. Jeffs E, Purushotham A, Springerplus, 2016 Jan ;5:21, The prevalence of lymphoedema in women who attended an information and exercise class to reduce the risk of breast cancer-related upper limb lymphoedema