

Painful lymphedema afflicts millions of patients after cancer surgery

By Ranit Mishori
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It's the aftershock of cancer surgery, a complication that breast cancer survivor Bonnie Pike of Phoenix calls "cancer treatment's dirty little secret," a nasty surprise that sneaks up on you.

- [Quiz: Test your knowledge of lymphedema](#)

Lymphedema, a painful and chronic swelling of the lymph nodes, may affect up to 70 percent of women who have undergone surgery or received radiation for breast cancer. Men who have undergone prostate cancer surgery often experience it as well. Yet the condition, estimated to afflict 3 million to 5 million Americans, is rarely discussed by doctors; it is sometimes ignored and frequently misdiagnosed, and it routinely goes untreated.



"My surgeon said he'd never had anybody ever develop it. . . . He still says that. It is just really hard for doctors to recognize it, for some radiation oncologists to admit" that it happens," Pike says.

Lymphedema is the accumulation of fluid at or near the site of cancer surgery - in the groin, the hands, the arms, the legs or the chest - as result of a blockage in the lymphatic system. That's the network of vessels running the length of the body through which lymphatic fluid travels to protect the body against invaders.

Scarring from surgery or radiation can cause such a blockage and the consequent buildup of fluid. This results in swelling, which in early stages can feel like nothing more than a slightly distracting tingling. Over time, however, the swelling can get worse, becoming painful, chronic and debilitating: restricting movement, impeding daily activities and requiring constant care. And once lymphedema appears, it can be hard to get rid of.

Says Judy Nudelman, a family physician at Brown University who is also a chronic lymphedema sufferer, "It affects everything I do," from playing tennis and getting dressed in the morning to flying in airplanes and even just sitting in the sun. "It's like everything I would do without thinking has to be thought through again," says Nudelman, whose lymphedema began after breast surgery.

People with lymphedema, according to a study last year in the journal *Family Relations*, tend to drop out of many activities, "either modifying the way they participated or not taking part."

Cancer surgery does not always lead to lymphedema, and there can be other causes of the painful condition. But there is strong evidence of cause and effect when cancer surgery is performed, because it often involves a surgical examination of nearby lymph nodes to determine whether the cancer has spread there as well. It does not really matter what kind of cancer is involved - whether it's prostate, melanoma, ovarian or something else - for there to be a risk of lymphedema, though most research has focused on its association with breast cancer.

Feeling abandoned

Yet as painful and common as lymphedema can be, it still gets very little attention in the medical literature, and, according to increasingly vocal patient groups, it is infrequently mentioned by doctors when discussing an upcoming cancer surgery or radiation treatment.

A Stanford University survey several years ago found that, on average, the lymphatic system gets only 15 minutes of attention during four years of instruction in medical school, and lymphedema may get no mention at all.

For Nudelman, who set out to raise awareness after her own problems began, one benchmark for this lack of interest is how often she hears that, as in her own case, lymphedema is "not even in the consent form" patients sign before surgery or radiation.

As a result, people who develop lymphedema after treatment often have a difficult time finding help for it. Pike, for instance, ended up going from one doctor to another after her a bilateral mastectomy resulted in lymphedema in both arms and her chest, and tried therapies that made things worse.

Along the way, she says, she also encountered medical practitioners who seemed to think she was just whining. Their attitude was, "I saved your life, now get on with it," she recalls. Pike says she was not surprised to read a study that said that women with lymphedema suffer not just from disability and disfigurement but also "from a feeling of abandonment by the medical community."

Pike uses massage and wears special garments 24 hours a day to deal with her condition.

Varying criteria

Nudelman says the frustration for many patients is that hospitals and doctors often tell them "we have zero incidence of lymphedema cases in our institution." Having treated some of those women, she says, she knows those claims don't hold up. But no hospital or individual surgeon wants a reputation for doing procedures that regularly result in complications, which is how they may view lymphedema.

Some of the problems may lie in the inconsistencies in the criteria used to identify lymphedema; this lack of standardization can mean that not all people experiencing most of the symptoms are recognized as having the condition. As a result, some estimates for lymphedema in women who have undergone breast cancer are as high as 70 percent, while others, using narrower criteria, put it as low as 6 percent.

Why such a wide variance? It mostly depends on how soon after surgery the studies focus on the symptoms, and on what body parts are examined. Immediately after surgery, the number of women showing symptoms is likely to be lower than later on because it takes time for the fluid to accumulate and begin to cause damage. At five years out, according to a 2008 study in the *Journal of Clinical Oncology*, 42 percent of women surveyed had reported symptoms.

Pike, whose battle with lymphedema pushed her to become an advocate, points out that patients are vulnerable "at any point after cancer treatment." "As more people survive," she says, "the more lymphedema we're obviously going to see, because the risk increases as time goes on."

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