

Lymphedema: How Nurses Can Be an Uplifting Resource

BY CYNTHIA WASHAM

How can nurses better meet lymphedema patients' needs? Ask the patients. Sheila H. Ridner, PhD, MSHA, MSN, RN, ACNP, asked 51 breast cancer patients with lymphedema to write their thoughts about the condition for 20 minutes, four times over the course of two weeks for her latest observational study on the condition. She said that although it wasn't something any of the women considered therapy, they told her, yet expressing their feelings in that way brought them relief, and some had long awaited interest from a medical professional.

"Breast cancer survivors often describe having lymphedema as worse than having cancer," said Ridner, Assistant Professor of Nursing at Vanderbilt University. "They received inadequate information from every health professional they



SHEILA H. RIDNER, PhD, MSHA, MSN, RN, ACNP: "Many breast cancer survivors with lymphedema, in an effort to become normal, quit doing self-care. We can help them find a regimen that doesn't take up all their lives....Nurses can encourage patients to live their lives and not to give up on social activities."



talked to. They felt dismissed and were frequently told, 'It's not cancer; go home and live with it.'"

Breast cancer-related lymphedema, characterized by extracellular lymph fluid that causes swelling, pain, and stiffness in the arm alongside the treated breast, is most often associated with node dissection, but can sometimes be linked to radiation therapy, explained Marybeth Singer, MS, ANP-BC, AOCN, ACHPN, an oncology nurse practitioner at Massachusetts General Hospital.

Some 25 to 40 percent of breast cancer survivors develop the condition, and symptoms are generally more severe in patients who have had axillary node rather than sentinel node dissection. The condition is most prevalent about 24 months after surgery, although it may linger for years and even decades. Ridner's findings on what patients reported improved quality of life while living with the condition were published in a recent article in *Supportive Care in Cancer* (2011;19.5:631-637).

What Really Bothers Patients

The greatest hardship, Ridner said she learned from the women in her study, is the emotional toll of living with a deformed arm.

"Body image disturbance was profound. They were sad and they were angry and they were grieving. They wanted to be normal, but never saw that happening."

Some women looked forward to cold weather because they could cover their arms with long sleeves. Others felt lymphedema created a barrier between them and their spouses that hadn't existed before their surgery, Ridner said.

Physicians may dismiss patients' concerns because there's no pill or

procedure to cure the problem. "I feel terrible when a patient gets a complication like that," said Henry Kuerer, MD, PhD, a breast surgeon at MD Anderson Cancer Center. "It's kind of a guilty conscience. Unfortunately, surgeons who do this surgery generally are not skilled in managing the complication or eliminating it. We feel powerless."

Standard of Care

While lymphedema has no cure, it can and often should be treated. The standard of care includes: physical therapy and self-massage to help circulate the lymph, exercise to strengthen the arm and chest muscles, compression bandages or garments, and meticulous skin care to prevent infections.

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Therapy is usually given by therapists trained in treating lymphedema. These specialists can be found through the National Lymphedema Network (lymphnet.org). The Lymphology Association of North

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America (crl-lana.org) provides training and certification to physicians, nurses, and therapists interested in treating lymphedema patients. In addition, Ridner noted, patients suffering emotionally from the burden of lymphedema often benefit from cognitive therapy.

The Nurse's Role Begins Even Before Surgery

The nurse's role in helping lymphedema patients should begin even before surgery. Ridner said she recommends a baseline evaluation including measurements of arm circumference, range-of-arm motion, and shoulder function.

Rebecca Crane-Okada, PhD, RN, CNS, AOCN, Assistant Professor in the Department of Nursing Research and Education at City of Hope, suggests that nurses continue assessing patients at every follow-up visit. If symptoms develop, they should then refer patients to a physical therapist.

Not all trained therapists are equally competent. Kuerer said he encourages oncology clinicians to get to know local lymphedema therapists and ask patients about their experiences with them.

Also key to the nurse's role, she said, is emphasizing the importance of

infection prevention. Nurses should advise patients to keep their skin very clean, to moisturize dry skin to prevent cracks, and to wear gloves when gardening or doing other dirty work. Nurses also should teach lymphedema patients how to treat minor wounds and to seek medical help immediately at the first sign of infection.

The National Lymphedema Network is promoting a bill that would expand Medicare coverage for therapy and add coverage for compression bandages and garments.

Another way nurses might help lymphedema patients is by encouraging them to lose weight, she said. The condition is known to be more prevalent in women who are overweight. A recent study in *American Journal of Occupational Therapy* (2010;64:59-72) suggests that losing weight after developing lymphedema might ease symptoms.

"Body mass index was very significant in increasing the risk for lymphedema," Singer said. "Weight loss after treatment may impact lymphedema, but that needs to be explored."

Treatment Roadblocks

Despite knowing interventions exist that ease symptoms, nurses should be aware of the barriers patients face in receiving treatment. Insurers' limits on lymphedema patients take away many treatment options from patients. Medicare limits therapy and does not cover compression products. The National Lymphedema Network is promoting the *Lymphedema Treatment Act*, which would expand Medicare coverage for therapy and add coverage for compression bandages and garments. NLN notes that although the legislation relates specifically to a change in Medicare law, it would almost certainly result in all private insurance policies following suit.

Whether or not patients are getting therapy, oncology nurses should continue

to encourage exercise, self-massage, and compression products, Crane-Okada emphasizes. Some old-school clinicians think patients should baby their affected arm, but plenty of research has demonstrated that exercise improves symptoms.

"We're seeing a new body of evidence that supports physical activity after breast cancer surgery in reducing lymphedema," Crane-Okada said.

"Don't tell them not to lift," Singer said. "That's a silly myth."

The Lymphedema Prognosis—and Where Nurses Fit

The incidence of lymphedema is expected to decline. A study published earlier this year in the *Journal of the American Medical Association* showed that full lymph node dissections are not beneficial for women treated with lumpectomy and radiation for early-stage breast cancer. Kuerer noted that some cancer centers, including MD Anderson, have already abandoned full dissection in these patients.

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Still, a number of patient will undergo dissections and develop lymphedema, and what they will need most from nurses, Ridner said, is support. Many patients give up on the care that could bring relief. Some find self-massage too time-consuming. They may feel compression garments draw more attention than their swollen arms do. "Many, in an effort to become normal, quit doing self-care. We can perhaps help them find a regimen that doesn't take up all their lives," she said.

Nurses can remain a support always to remind patients how they can ease symptoms and deal with a lymphedema diagnosis, Ridner said. "Nurses can encourage patients to live their lives and not to give up on social activities. We can become an uplifting resource." 



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