

# Post-Breast Cancer Lymphedema: Understanding Women's Knowledge of Their Condition

M. Elise Radina, PhD, CFLE, Jane M. Armer, PhD, RN,  
Scott D. Culbertson, BS, and Julie M. Dusold, BA

**Purpose/Objectives:** To investigate chronic condition representations and treatment choices among women with post-breast cancer lymphedema (LE) to understand their receipt and use of accurate medical information.

**Design:** Qualitative, template analysis.

**Setting:** Midsized midwestern city and surrounding rural areas.

**Sample:** 18 Caucasian women aged 37–87 years ( $\bar{X}$  = 58.8 years) with LE.

**Methods:** Telephone and face-to-face interviews, lasting 45–60 minutes, were conducted by research students and graduate nursing students. Interviews were audiotaped, professionally transcribed, and verified for transcription accuracy. Self-regulation theory as a template was applied to (a) understand participants' use of health information to cope with LE and (b) evaluate the accuracy of participants' health information that may have influenced participants' abilities to make appropriate prevention or treatment choices.

**Main Research Variables:** Participants' illness representations and coping strategies.

**Findings:** Participants were aware of the fundamental cause of their LE—breast cancer treatment. They also were conscious of other causes of symptom onset. These causes are supported by existing empirical evidence. Participants' treatment choices were consistent (e.g., use of compression treatment, massage, elevation, pumps, therapists and therapy centers, and positive attitude and faith) and inconsistent (e.g., effectiveness of exercise and medication in management of LE) with empirical evidence.

**Conclusions:** Future research and practice should target the role of exercise as a cause of LE and as a treatment option, investigate allergic reactions as a possible catalyst of LE symptoms, work to improve diagnosis of LE and patient education, and examine the effectiveness of medications as a treatment method.

**Implications for Nursing:** Review of LE risk factors in the postoperative period and continued assessment and education are vital to a comprehensive approach to post-breast cancer LE care.

## Key Points . . .

- Ignorance about the symptoms of lymphedema (LE) among medical professionals has led to the use of inappropriate or inadequate courses of treatment; this is evident because not enough treatment centers, certified LE therapists, and other medical professionals are prepared to treat LE.
- Among patients with breast cancer, those who receive radiation therapy or surgical resection of axillary lymph nodes are at the greatest risk for developing upper-extremity LE.
- Patients may not be knowledgeable about effective LE treatment, such as complex decongestive physiotherapy, which involves manual lymphatic drainage, skin care, compression, and exercise to decrease limb volume.

use of inappropriate or inadequate courses of treatment (Földi, 1998). Presently, the United States does not have enough treatment centers (currently 158), certified LE therapists (currently 357), and other medical professionals who are prepared to treat LE (Lymphology Association of North America [LANA], 2002; National Lymphedema Network [NLN], 2002b; Rinehart-Ayers, 1998). Others have argued that patients' unawareness about LE is a result of the method and timing of post-breast cancer LE risk communication (Passik & McDonald, 1998).

The focus of the present study is the accuracy of patient knowledge about LE. Specifically, research has suggested that many women with LE do not know or understand the risk of LE, what caused their LE, and how to treat LE (Radina & Armer, 2001; Thiadens et al., 2002). Self-regulation theory guided the development of the research question for this study: What do the chronic condition representations and management choices of patients with LE indicate about their knowledge of accurate medical information and their use of this information?

*M. Elise Radina, PhD, CFLE, is an assistant professor of family services at the University of Northern Iowa in Cedar Falls; Jane M. Armer, PhD, RN, is an associate professor in the MU Sinclair School of Nursing and director of nursing research at Ellis Fischel Cancer Center, and Scott D. Culbertson, BS, and Julie M. Dusold, BA, are research specialists in the MU Sinclair School of Nursing, all at the University of Missouri–Columbia. (Submitted September 2002. Accepted for publication April 3, 2003.)*

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**I**ncreasing numbers of women are surviving breast cancer as a result of innovations in technologies for breast cancer detection and treatment (Ganz, 1999). However, an estimated one-third of women who undergo breast surgery involving the removal or irradiation of the axillary lymph nodes develops secondary lymphedema (LE) of the arm (Chu et al., 1996; Ganz).

Studies have shown that many women who are at risk for developing post-breast cancer LE perceive that they did not receive adequate education about LE at the time of surgery (Thiadens, Armer, & Porock, 2002; Woods, 1993). Runowicz (1998) argued that this might occur because most healthcare providers do not receive formal training about LE risk, prevention, and treatment. This has resulted in worldwide ignorance about LE symptoms, leading to late diagnosis and the