Increasing 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 use of inappropriate or inadequate courses of treatment (Földi, 1998). Presently, the United States does not have enough treatment centers, certified LE therapists, 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?

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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.