Since Carter’s (1997) sentinel study of breast cancer survivors’ experiences with lymphedema, articles have evaluated how those individuals perceive (Radina, Armer, Culbertson, & Dusold, 2004) and manage their condition (Fu, 2005), as well as the impact of lymphedema on physical and psychological health (Thomas-MacLean, Miedema, & Tatemichi, 2005; Towers, Carnevale, & Baker, 2008). Additional studies examined health outcomes (Ahmed, Schmitz, Prizment, & Folsom, 2011; Pyszel, Malyszczak, Pyszel, Andrzejak, & Szuba, 2006), physical activities (Schmitz et al., 2010), symptom clusters (Ridner, 2005), and self-care (Ridner, Dietrich, & Kidd, 2011). Those studies, along with others, identified distressing physical, psychosocial (Rosedale & Fu, 2010), sexual (Radina, Watson, & Faubert, 2007), and quality-of-life difficulties in these patients. Those results have led some to view breast cancer treatment–related lymphedema as a disabling condition and to suggest that a disability model should be used with these patients (Bosompra, Ashikaga, O’Brien, Nelson, & Skelly, 2002; Tsauo, Hung, Tsai, & Huang, 2011). Therefore, lymphedema management commonly is viewed as the responsibility of rehabilitation-oriented lymphedema therapists rather than nurses.

Despite well-documented difficulties, breast cancer survivors with lymphedema must create a framework for daily living. Little is known about how these individuals structure their daily lives. That information is needed to broaden the understanding of whether patients with lymphedema live with a perceived disability and withdraw from life, or engage life as nondisabled people. That information can guide holistic approaches to patient management and provide oncology nurses with valuable information for supportive education, interventions, and care.

This mixed-methods study collected symptom data and explored four topics related to the daily lives of breast cancer survivors with lymphedema: eating habits, daily activities, substance use, and future plans. These women had served as the control group of writers in a larger randomized clinical trial that tested the effectiveness of expressive writing in improving health outcomes in breast cancer survivors with chronic stage II lymphedema (International Society of Lymphology, 2009; Ridner, Bonner, Deng, & Sinclair, 2012).