

# Breast Cancer Survivors With Lymphedema: Glimpses of Their Daily Lives

Sheila H. Ridner, PhD, RN, FAAN, Vaughn Sinclair, PhD, RN, Jie Deng, PhD, RN, Candace M. Bonner, BSW, RN, Nancy Kidd, BS, and Mary S. Dietrich, PhD



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Breast cancer survivors with lymphedema experience physical, psychosocial, and quality-of-life difficulties. Cancer treatment–related lymphedema often is viewed as a disabling condition, and that assumption has fostered an environment in which oncology nurses are not actively involved in the care of patients with lymphedema. Little is known about how breast cancer survivors with lymphedema structure their daily lives. This article describes an effort to determine whether lymphedema truly is a disabling condition by collecting symptom data and self-generated narratives from breast cancer survivors with lymphedema regarding their eating habits, daily activities, substance use, and future plans. Although the sample experienced multiple symptoms, lymphedema duration and degree of extracellular arm fluid did not appear to influence those symptoms.

In addition, participants led full, rich, busy lives. The findings do not support the notion that patients with lymphedema live as disabled people. A disability model may not be optimal to guide research design or patient care; rather, a symptom management model better explains the findings and implies that active involvement by nurses in lymphedema patient care and education is indicated.

Sheila H. Ridner, PhD, RN, FAAN, and Vaughn Sinclair, PhD, RN, are professors of nursing, Jie Deng, PhD, RN, is an assistant professor of nursing, Candace M. Bonner, BSW, RN, is an RN-research II, and Nancy Kidd, BS, is a research assistant III, all in the School of Nursing; and Mary S. Dietrich, PhD, is a research associate professor in the Schools of Medicine and Nursing, all at Vanderbilt University in Nashville, TN. The authors take full responsibility for the content of the article. Funding for this work was received from the American Cancer Society (#MRS-07-012-01-CPPB). The content of this article has been reviewed by independent peer reviewers to ensure that it is balanced, objective, and free from commercial bias. No financial relationships relevant to the content of this article have been disclosed by the independent peer reviewers or editorial staff. Ridner can be reached at [sheila.ridner@vanderbilt.edu](mailto:sheila.ridner@vanderbilt.edu), with copy to editor at [CJONEditor@ons.org](mailto:CJONEditor@ons.org). (First submission January 2012. Revision submitted May 2012. Accepted for publication May 27, 2012.)

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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 respon-

sibility 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).