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The Role of Information Sources and Objective Risk Status on Lymphedema Risk-Minimization Behaviors in Women Recently Diagnosed With Breast Cancer

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Purpose/Objectives: To assess the role of education sources and objective risk status on knowledge and practice of lymphedema risk-minimization behaviors among women recently diagnosed with breast cancer.

Research Approach: Prospective survey.

Setting: A hospital in Sydney, Australia.

Participants: 106 women recently diagnosed with breast cancer at increased risk for developing lymphedema following lymph node dissection.

Methodologic Approach: A questionnaire administered at the time of surgery and three months after surgery measured demographics, lymphedema knowledge, lymphedema information sources used, and adherence to risk-minimization recommendations.

Main Research Variables: Lymphedema knowledge, source of information used, objective lymphedema risk, and adherence to risk-minimization behaviors.

Findings: Knowledge was high and increased over time. Lymphedema information from the clinic (e.g., brochures, nursing staff) was the most cited source. Adherence to recommendations was moderate; nonadherence was mostly for behaviors requiring regular enactment. Regression analysis revealed that only receipt of information from nursing staff and lymphedema knowledge three months after surgery were significant predictors of risk-minimization behaviors.

Conclusions: Exposing women to lymphedema risk information at the time of breast cancer diagnosis facilitates increased awareness and enactment of risk-minimization behaviors. Nursing staff play a key role in disseminating this information and in convincing women to perform the recommendations.

Interpretation: Provision of lymphedema education by breast clinic staff is critical to ensure that women realize the importance of early detection and treatment. Reminder booster sessions by nursing staff may be beneficial particularly for longer-term knowledge retention and adherence to recommended behaviors.

Lymphedema, characterized by long-term arm swelling from disruption of the lymph nodes (Moffatt et al., 2003), is a physically debilitating condition that may develop following breast cancer surgery and treatment (Erickson, Pearson, Ganz, Adams, & Kahn, 2001; Loudon & Petrek, 2000). An estimated 20% of people treated for breast cancer will develop lymphedema (Hayes, Janda, Cornish, Battistutta, & Newman, 2008). Removal or irradiation of axillary lymph nodes (Bani et al., 2007; Goffman, Laronga, Wilson, & Elkins, 2004; van der Veen et al., 2004), infections, and obesity (Ridner & Dietrich, 2008; Swenson, Nissen, Leach, & Post-White, 2009) are known lymphedema risk factors. Compromised quality of life and psychological morbidity during short- and long-term survivorship have been associated with lymphedema (Armer, 2005; Greenslade & House, 2006; Mansel et al., 2006). Sentinel lymph node biopsy (SLNB), a less invasive surgical technique than axillary lymph node dissection (ALND), has reduced lymphedema incidence (Francis et al., 2006; Lucci et al., 2007) up to one year postsurgery (Langer, Guenther, Haigh, & Difronzo, 2004; Mansel et al., 2006; Purushotham et al., 2005). However, not all women are candidates for SLNB, and at least 35% of women who initially undergo SLNB return later for ALND following the detection of more extensive cancer (Husen, Paaschburg, & Flyger, 2006; Langer et al., 2007; Leidenius, Leivonen, Vironen, & von Smitten, 2005). Therefore, despite the availability of less invasive surgical techniques, a substantial number of women with breast cancer will undergo procedures that increase their objective lymphedema risk (Cheville, 2007).

Any means by which lymphedema risk can be minimized is beneficial. National breast cancer organizations publish guidelines that recommend lifetime adoption of strategies to minimize lymphedema risk and highlight the importance of early detection and treatment if