

# Factors Associated With Fear of Lymphedema After Treatment for Breast Cancer

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**B**reast cancer survivors are at a lifelong risk of developing lymphedema, a chronic upper extremity morbidity that can occur secondary to breast cancer treatment. Lymphedema is characterized by the abnormal accumulation of protein-rich fluid in the interstitial spaces of the arm, hand, shoulder, breast, or chest wall, and is often accompanied by symptoms of swelling, heaviness, and discomfort (Armer, Radina, Porock, & Culbertson, 2003; Armer & Stewart, 2010). Survivors with lymphedema are at an increased risk for infection (Shih et al., 2009) and may experience functional impairment (Armer et al., 2003). The psychological distress caused by lymphedema can adversely affect body image, lower self-esteem, and increase anxiety (Chachaj et al., 2010; Ridner, 2005). Together, the physical and psychological detriments of lymphedema have been shown to significantly reduce overall quality of life (QOL) (Ahmed, Prizment, Lazovich, Schmitz, & Folsom, 2008; Ridner, 2005).

Because of its difficulty to predict, lack of definitive treatment, and negative impact on QOL, many survivors fear developing lymphedema. Even the possibility of developing lymphedema or worsening existing lymphedema has been shown to cause fear and worry among breast cancer survivors (Collins, Nash, Round, & Newman, 2004; Erickson, Pearson, Ganz, Adams, & Kahn, 2001; McLaughlin et al., 2013). As a result, many women engage in risk-reducing behaviors (McLaughlin et al., 2013). Common risk-reduction practices supported by the National Lymphedema Network (INLN, 2012) include use of compression garments (particularly for air travel), skin care to avoid trauma or injury that may lead to infection (e.g., avoiding skin punctures such as injections or blood draws, use of sunscreen to protect exposed skin), avoidance of limb constriction (blood pressures, tight clothing), and avoidance of extreme temperatures. However, most of these risk-reduction strategies lack scientific evidence supporting their efficacy. Instead, most are based on expert opinion gathered through decades of clinical experience and understanding of the condition's patho-

**Purpose/Objectives:** To identify demographic and treatment characteristics associated with postoperative fear of lymphedema.

**Design:** Prospective cohort study.

**Setting:** Outpatient breast clinic at a comprehensive cancer center in the northeastern United States.

**Sample:** 324 patients undergoing treatment for unilateral breast cancer.

**Methods:** Women with breast cancer were prospectively screened for lymphedema (relative volume change of 10% or greater) preoperatively and every three to eight months postoperatively via Perometer arm volume measurements. Fear was simultaneously evaluated via questionnaire. Multivariate linear mixed-effects regression models were used to identify factors associated with mean postoperative fear score and to plot the average fear score over time within axillary surgery type subgroups.

**Main Research Variables:** Postoperative fear of lymphedema.

**Findings:** Higher preoperative fear score ( $p < 0.0001$ ), younger age at diagnosis ( $p = 0.0038$ ), and axillary lymph node dissection (ALND) ( $p < 0.0001$ ) were significantly associated with higher mean postoperative fear score. The average fear score changed nonlinearly over time ( $p < 0.0001$ ), decreasing from preoperative to 24 months postoperative and leveling thereafter.

**Conclusions:** Preoperative fear, younger age at diagnosis, and ALND may contribute to postoperative fear of lymphedema.

**Implications for Nursing:** Individualized education that begins preoperatively, continues throughout treatment, and is re-emphasized 24 months postoperatively may help minimize fear of lymphedema.

**Key Words:** lymphedema; breast cancer; fear; Perometer; quality of life

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physiology (Cemal, Pusic, & Mehrara, 2011; McLaughlin, 2012; National Lymphedema Network, 2012).

Fear of lymphedema can also affect decisions about engaging in physical activity and exercise. It has