Factors Associated With Fear of Lymphedema After Treatment for Breast Cancer

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Breast 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 (NLN), 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 pathophysiology (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...