© Oncology Nursing Society. Unauthorized reproduction, in part or in whole, is strictly prohibited. For permission to photocopy, post online, reprint, adapt, or otherwise reuse any or all content from this article, e-mail pubpermissions@ons.org. To purchase high-quality reprints, e-mail reprints@ons.org.

Article

Information for Patients With or at Risk of Cancer-Related Lymphedema: An Evaluation of Web Sites

Sylvie Dubois, RN, PhD, and Nathalie Folch, PhD



© iStockphoto/Thinkstock

The Internet has great potential to provide information to patients with or at risk of developing cancer-related lymphedema (CRL), a complication of cancer treatment. To evaluate Web site structure (e.g., accreditation, design) and content (e.g., validity) for available Web sites on CRL, lymphedema, lymphoedema, cancer, and oncology were used with 10 search engines (five French and five English). The first page of each Web site was examined and the content was identified and classified using the evaluation model of the Science Panel on Interactive Communication and Health. The search strategy yielded 120 Web sites. Using inclusion and exclusion criteria, 19 Web sites were selected. The authors found that 79% of the Web sites focused exclusively on CRL and 74% were in English. Although information about each site's sponsor, goal, and target

audience was readily available, content material was incomplete and evaluation of Web site impact and effectiveness was nonexistent. This review suggests that Web sites about CRL vary greatly in terms of structure and content.

Sylvie Dubois, RN, PhD, is the director of nursing at the Direction of Nursing and a professor in the Faculty of Nursing, and Nathalie Folch, PhD, is a research consultant at the Direction of Nursing, both at the University of Montreal Hospital Center in Canada. The authors take full responsibility for the content of the article. This work was supported in part by the Direction of Nursing at the University of Montreal Hospital Center, the University of Montreal, and an institutional grant from the Social Sciences and Humanities Research Council of Canada. The authors did not receive honoraria for this work. 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. Dubois can be reached at sylvie.dubois@umontreal.ca, with copy to editor at CJONEditor@ons.org. (Submitted December 2012. Revision submitted February 2013. Accepted for publication March 24, 2013.)

Digital Object Identifier:10.1188/13.CJON.533-538

ancer survival rates are increasing every year (National Cancer Institute, 2011). However, this also presents other challenges, including issues such as an increase in reported cases of lymphedema, a condition that may occur after surgical treatment, radiation therapy, or both. Cancer-related lymphedema (CRL) is a chronic condition that may contribute to impairment in range of limb motion, loss of strength, and functional limitations with activities, therefore decreasing quality of life (Medical Services Advisory Committee, 2004; Shih et al., 2009). CRL also can have significant economic consequences (Beaulac, McNair, Scott, LaMorte, & Kavanah, 2002); for example, it represents an average annual expense of \$3,125 per patient (Stout et al., 2012). The physiologic insufficiency of the lymph system leads to the accumulation of fluid in the interstitial tissues, which can happen immediately after treatment or even several months or years later (International Society of Lymphology [ISL], 2003; Lymphoedema Framework, 2006). Although the number of individuals suffering from CRL is not known, Rockson and Rivera (2008) estimated that 2–3 million people in the United States may be affected by CRL or primary lymphedema, a hereditary or congenital problem (e.g., lymphatic system malformation).

Several studies have shown varying percentages of CRL depending on the type of cancer (Armer, 2005; Cormier et al., 2010; Crane-Okada & Loney, 2007). For breast cancer, the reported incidence is around 5%–20% (Rockson & Rivera, 2008), although the percent varies widely from 6%–63% depending on the study population, measurement scale, and length of follow-up (Armer, 2005, 2010). Based on a systematic review and meta-analysis, Cormier et al. (2010) showed that the overall incidence of lymphedema in conditions other than breast cancer is 16% and varies with site of malignancy (sarcoma, 30%; lower extremity, 28%; gynecologic, 20%; melanoma, 16%; genitourinary, 10%; upper extremity, 5%; and head and neck, 4%). In addition, the risk for developing lymphedema increases for patients undergoing radiation therapy (31%) and pelvic dissections (22%).