The Experience of Lower Limb Lymphedema for Women After Treatment for Gynecologic Cancer

Mary Ryan, RN, BN(Hons), M. Colleen Stainton, RN, BSN, MN, DSN, Carmel Jaconelli, RN, DipAppIScience(Nurs), GradDip(MedSurgNurs), Sally Watts, RN, Patricia MacKenzie, RN, BA, and Tamar Mansberg, BSc, DipPhysio

Purpose/Objectives: To describe women’s experiences with lower limb lymphedema to inform both preventive and management clinical practices.

Design: A retrospective survey.

Setting: The gynecology/oncology unit of a tertiary referral women’s hospital in Australia.

Sample: 82 women who developed lower limb lymphedema after surgical and radiation treatment for gynecologic cancers.

Methods: Structured interviews.

Main Research Variables: Psychosocial and emotional impact, physical effects, knowledge, support, treatment modalities.

Findings: Women identified changes in appearance and sensation in the legs and the triggers that both preceded and exacerbated symptoms. Women described seeking help and receiving inappropriate advice with as many as three assessments prior to referral to lymphedema specialists. Many women implemented self-management strategies. Lower limb lymphedema had an impact on appearance, mobility, finances, and self-image.

Conclusions: Increasing longevity after gynecologic oncology treatment requires all practitioners to be aware of known or potential triggers of lower limb lymphedema and the appropriate referral and management strategies available. Women at risk need to know early signs and symptoms and where to seek early care.

Implications for Nursing: The role of nursing in acute and community care of women at risk for developing lower limb lymphedema includes (a) engaging women in protecting their legs from infection or trauma pre- and postoperatively, (b) providing nursing care and education during the pre- and postoperative phases, and (c) ensuring that women being discharged are aware of early signs and symptoms of lower limb lymphedema and how to access qualified, specialized therapists so that early and effective management can be initiated.

Advances in surgical procedures, chemotherapy, and radiation have significantly reduced mortality from the major cancers of the female reproductive system, thus increasing longevity. Reducing sequelae that may affect quality of life is an important consideration in contemporary gynecologic cancer care. Although women may be cured from these cancers, subsequent morbidity such as lower limb lymphedema can be debilitating and require intensive, costly treatment. Few documented studies exist that focus primarily on this symptom.

Lymphedema is a chronic condition that may develop after removal of or radiotherapy to lymph nodes. Lymphedema occurs when the lymphatic system is unable to maintain tissue fluid homeostasis, resulting in accumulation of protein-rich lymph fluids in the interstitial spaces of subcutaneous tissue (Logan, 1995). Lymphedema can lead to distortion of size, shape, and function of affected extremities. No standardized guidelines are available for nursing care in the pre- and postoperative periods for women undergoing gynecologic cancer surgery involving lymph node dissection. Knowledge is needed that will inform a dynamic multidisciplinary model of continuous care for those at risk for developing lower limb lymphedema after gynecologic cancer treatment.

Researchers can only hypothesize that lymphedema in one or both legs will encroach on a woman’s quality of life and well-being after an experience with a potentially fatal disease.

Key Points . . .

➤ Development of lower limb lymphedema erodes women’s sense of full recovery after treatment for gynecologic cancer.

➤ All healthcare practitioners require more knowledge of early warning signs and appropriate referral for care of lower limb lymphedema.

➤ Women at risk require predischARGE information about the possibility of developing lower limb lymphedema and where to seek early and appropriate treatment.

Mary Ryan, RN, BN(Hons), is a clinical nurse consultant in the Gynaecological Cancer Centre of the Royal Hospital for Women in Randwick, New South Wales, Australia; M. Colleen Stainton, RN, BSN, MN, DSN, is the chair of women’s health nursing and a professor in the Faculty of Nursing at the University of Sydney and Centre for Women’s Health Nursing, Royal Hospital for Women; Carmel Jaconelli, RN, DipAppIscience(Nurs), GradDip(MedSurgNurs), is a research nurse for this Lower Limb Lymphedema Project; and Sally Watts, RN, is a nursing unit manager, Patricia MacKenzie, RN, BA, is a clinical nurse consultant, and Tamar Mansberg, BSc, DipPhysio, is a physiotherapist, all at the Gynaecological Cancer Centre of the Royal Hospital for Women. This study was supported by a donation for nursing research from a family after a personal experience with the unit and a research award from the Royal Hospital for Women Foundation. (Submitted February 2002. Accepted for publication July 30, 2002.)

Digital Object Identifier: 10.1188/03.ONF.417-423