Caregiver Burden in End-Stage Ovarian Cancer

Joan Hartnett, MS, RN, ANP-BC, AOCNP®, Bridgette Thom, MS, and Nancy Kline, PhD, RN, CPNP, FAAN

Background: Caregiver burden associated with caring for women with ovarian cancer has received limited focus. However, these patients often have complex needs, requiring a high level of care at home and imposing substantial burdens on caregivers.

Objectives: This pilot study assessed the level of caregiver burden experienced by the primary caregivers of patients with end-stage ovarian cancer and identified variables associated with caregiver burden.

Methods: Caregiver burden was assessed using the Caregiver Reaction Assessment. Fifty caregivers completed an anonymous and voluntary survey. Pearson correlations and independent samples t-tests were used to analyze data.

Findings: Most participants were Caucasian, married or living with a partner, and college graduates, with an annual household income of less than $90,000. Caregiver ages ranged from 29–81 years. Participants agreed most with the self-esteem scale, indicating they had pride in caring for their loved ones. Disrupted schedules and financial problems were the most burdensome factors in providing care. Because financial issues affected caregiver burden, nurses should facilitate interdisciplinary support. Future research is needed to determine the impact of nurse-led interventions to reduce caregiver burden.

Epithelial Ovarian Cancer and Treatment

About 22,280 U.S. women will receive a new diagnosis of ovarian cancer in 2016, and about 14,240 women will die from this disease in the same year (American Cancer Society [ACS], 2016). Advances in the treatment of ovarian cancer have led to increased survival and the consideration of ovarian cancer as a chronic disease. This shift has required more care outside of the hospital setting by caregivers who are often left to provide complicated care and support in the home. This pilot study explores the concept of caregiver burden among caregivers of women with end-stage ovarian cancer.

Staging of ovarian cancer includes abdominal washing cytology, peritoneal biopsies, bilateral salpingo-oophorectomy, hysterectomy, infracolic omentectomy, pelvic lymph node dissection, and para-aortic lymph node dissection. Only about 20% of women with ovarian cancer are diagnosed with early-stage disease (stage I A and IB) in which the cancer is confined to the ovary, and treatment is of curative intent; 90%–100% of these patients are cured of their disease (National Comprehensive Cancer Network [NCCN], 2015). For early-stage disease, the NCCN treatment guidelines recommend debulking surgery, in which only the affected ovary is removed, and then observation, which includes computed tomography scans and follow-up with an oncologist every three to six months for three years, and then annually for five years (Cass & Karlan, 2003; NCCN, 2015).

However, 60% of patients are diagnosed with advanced stages of disease (stage III or IV), and outcomes are much graver than for those with earlier-stage diagnoses. About 36% of women with stage III ovarian cancer survive five years after their diagnosis, and 18% of patients with stage IV disease survive for this period (Stewart, Rim, & Richards, 2011). If the disease has spread beyond the ovary, a total abdominal hysterectomy and bilateral