Multidimensional Needs of Caregivers for Patients With Cancer

Karen A. Skalla, MSN, AOCN®, ARNP, Ellen M. Lavoie Smith, PhD, ANP-BC, AOCN®, Zhongze Li, MS, and Charlene Gates, PT

This pilot study describes the multidimensional (physical, psychological, social, and spiritual) needs of caregivers of cancer survivors. A regional comprehensive cancer center and nine community-based rural and urban cancer clinics in New Hampshire assembled a convenience sample. Patients with cancer completed an online survey, the cancer survivor Web-based needs assessment survey (CS-WEBS), to identify needs and desire for intervention. Patients then identified a caregiver who was recruited to complete a caregiver version of the CS-WEBS. Caregivers reported challenges within all four domains of the survivorship model. The highest reported physical symptoms were fatigue, insomnia, and weight gain. Social symptoms included financial issues. Although visiting nurse services were the most commonly used resource, many caregivers used no supportive services. The most common caregiver task was listening and talking. Caregivers frequently experienced fatigue, anxiety, and insomnia. Exploring effective ways to alleviate their symptom burden should be a priority. Local and national attention should be directed toward easing the financial burden of caring for a patient with cancer.

The Centers for Disease Control and Prevention (2004) defined cancer survivors as “people who have been diagnosed with cancer and those people in their lives who are affected by the diagnosis, including family members, friends, and caregivers” (p. 2). As of 2008, 4.6 million Americans provided home-based care for patients with cancer (National Alliance for Caregiving, 2009). Many studies have examined the cancer caregiving experience (Braun, Mikulincer, Rydall, Walsh, & Rodin, 2007; Carney et al., 2011; Hasson-Ohayon, Goldzweig, Braun, & Galinsky, 2010; Kim, Kashy, Spillers, & Evans, 2010; Pellegrino et al., 2010). Caregivers of cancer survivors experience a wide variety of difficulties, specifically physical symptoms, psychosocial and mental health issues, economic difficulties, and spiritual issues (Braun et al., 2007; Carney et al., 2011; Cross & Emanuel, 2008; DuBenske, Chih, Gustafson, Dinauer, & Cleary, 2010; Given, Given, & Sherwood, 2012; Madsen & Poulsen, 2011; Northfield & Nebauer, 2010; Pellegrino et al., 2010; Rhee et al., 2008; Schumacher et al., 2008; Sherwood, Donovan, et al., 2008; Sherwood, Given et al., 2008; Stenberg, Ruland, & Miaskowski, 2010; Surbone et al., 2010; Swore Fletcher, Dodd, Schumacher, & Miaskowski, 2008; Van Houten, Ramsey, Hornbrook, Atienza, & van Ryn, 2010; van Ryn et al., 2011; Yabroff & Kim, 2009). Research to date has focused on singular dimensions of the caregiving experience (e.g., psychological, physical, spiritual) rather than the cumulative, multidimensional experience.

Several studies suggest that caregivers are not receiving adequate assistance to cope with caregiving challenges (Adams, Boulton, & Watson, 2009; Given et al., 2012; Kim et al., 2010; Kinnane & Milne, 2010; Madsen & Poulsen, 2011; Swore Fletcher et al., 2008). However, despite current evidence, significant gaps in the knowledge remain. For example, psychological and informational needs have been the focus of most studies (Adams et al., 2009; Blum & Sherman, 2010; Daly, Douglas, Lipson, & Foley, 2009; DuBenske et al., 2010; Hasson-Ohayon et al., 2010; Kinnane & Milne, 2010; Northfield & Nebauer, 2010; Pellegrino et al., 2010; Schumacher et al., 2008). Few studies have focused...