



Putting Together the Pieces of the Puzzle: Identifying Existing Evidence-Based Resources to Support the Cancer Caregiver

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Caring for the caregivers of patients with cancer is an increasingly important part of cancer care. In the past few years, several cancer centers have started caregiver-focused services and programs. However, the number of centers that offer such programs and what they provide is unclear. This article will review the extent to which the 61 National Cancer Institute–designated cancer centers that primarily provide patient care also offer evidence-based support programs for caregivers.

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For most of the estimated 1.6 million Americans who will be diagnosed with cancer in 2014, at least one family member or other caregiver will also be affected by the diagnosis (American Cancer Society, 2014). These informal caregivers often provide physical, emotional, financial, and spiritual support to patients, which is a task that sometimes stretches them beyond their capabilities or resources (Given, Given, & Sherwood, 2012). In addition to helping patients and jointly managing the stressors associated with the illness, cancer caregivers often have their own specific issues (Li & Loke, 2013; Mosher, Bakas, & Champion, 2013; Northouse, Williams, Given, & McCorkle, 2012; Stenberg, Ruland, & Miaskowski, 2010).

All of this care can take a toll. Researchers have identified numerous negative physical, psychological, and social outcomes in caregivers (Bevans & Sternberg, 2012; Given et al., 2012; Northouse, Williams, et al., 2012; Stenberg et al., 2010).

A national study of caregivers of people diagnosed with varying illnesses found fatigue, stress, increased pain, depression, headaches, and weight changes to be among the most frequent complaints (Evercare & National Alliance for Caregiving, 2006). More specific to cancer caregivers, a 2010 systematic review of the effects of caregiving cited physical ailments such as pain, problems with sleep, decreased energy, reduced strength, and loss of appetite (Stenberg et al., 2010). The same review elucidated the emotional challenges for caregivers, including anxiety, depression, fear, a sense of hopelessness or helplessness, and uncertainty; caregiver anxiety and depression was sometimes worse for caregivers than for patients (Northouse, Williams, et al., 2012; Stenberg et al., 2010). Caregivers are socially challenged on multiple fronts: missing time at work, losing income or savings, juggling changing roles and responsibilities, coping with schedule interruptions and lost leisure time,

and facing isolation (Bevans & Sternberg, 2012; Skalla, Smith, Li, & Gates, 2013; Stenberg et al., 2010). The emotional downsides to caring for patients with cancer are somewhat balanced by positive experiences (e.g., appreciating time together, having a greater sense of connectedness) (Stenberg et al., 2010).

A number of cancer centers have started caregiver-focused services and programs, although the amount and what the centers provide remain unclear. This article reviews the extent to which 61 National Cancer Institute (NCI)-designated cancer centers offer evidence-based support programs focused on patient caregiving, marital and family care, and caregiver self-care (Northouse, Katapodi, Song, Zhang, & Mood, 2010). The authors also make recommendations for leveraging the programs already in place and address other political, financial, and practice obstacles. In this way, healthcare providers can tap into existing resources to reduce the stress placed on cancer caregivers and to help them continue to support patients and care for themselves.

Methods

The authors identified a group of cancer centers that could represent the broader collective of cancer-focused institutions across the country. Sixty-eight institutions have been designated by the NCI as cancer centers ($n = 27$) and as comprehensive cancer centers ($n = 41$), and they are characterized by their demonstrated excellence in cutting-edge cancer research, training for future scientists and healthcare providers, state-of-the-art patient care, and public education about cancer prevention and screening