
Caregiver Café

Providing education and support to family caregivers of patients with cancer

Joanne P. Finley, RN, MS

BACKGROUND: The many burdens faced by caregivers of patients with cancer are well documented. Caregivers are asked to perform procedures, make assessments, coordinate care, and communicate with healthcare providers at an increasingly complex level. A caregiver quality improvement project, in the form of a Caregiver Café, was instituted at a National Cancer Institute–designated comprehensive cancer center.

OBJECTIVES: The objectives of the café are to (a) provide respite and a place for caregivers to relax and be nurtured, (b) provide a place for caregivers to meet and support each other, (c) provide answers to caregiver questions, and (d) recommend appropriate caregiver resources.

METHODS: The weekly Caregiver Café is led by an advanced practice nurse, and the format varies depending on the needs of the caregivers who attend.

FINDINGS: Caregivers have verbalized the importance of the café in helping them cope with their loved ones' cancers and treatments, and many attend on a regular basis. The Caregiver Café provides support and information and a place to get away from it all.

KEYWORDS

family caregivers; support; education; intervention; informal setting

DIGITAL OBJECT IDENTIFIER

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CAREGIVERS OF PATIENTS WITH CANCER experience a higher level of burden than caregivers of older adults and a similar level of burden to caregivers of patients with dementia (Kim & Schulz, 2008). Today's cancer treatments, including chemotherapy, radiation therapy, biotherapy, and stem cell transplantations, are primarily administered in outpatient settings. This is beneficial to patients who would prefer to remain in their homes but is more stressful for their caregivers, who perform much of their care without extensive preparation or education. Potter et al. (2010) documented the numerous learning needs of patients with cancer and their caregivers. The top three activities that caregivers said they would like to know more about were helping patients deal with their feelings about cancer, watching for infection, and managing side effects. An early study of caregiving burden (Carey, Oberst, McCubbin, & Hughes, 1991) found that providing emotional support for patients was the most demanding activity, as did a more recent study by Copley Cobb, Etkins, Nelson, Egleston, and Sweeney (2016).

Many researchers have identified the significant strain that a diagnosis of cancer, and the subsequent care and support that is needed, places on caregivers. Physical manifestations of this strain may include fatigue (Schumacher et al., 2008) and worsened general health (Bevans & Sternberg, 2012). Emotional manifestations include anxiety, depression, and stress. Halpern, Fiero, and Bell (2017) reviewed national survey responses of caregivers of patients with cancer and categorized their responses into emotional and psychological burden and relationship with the patient. Certain patient care tasks have more effect on different types of burden. For example, help with personal care and help with getting around were associated with a higher emotional burden for caregivers (Halpern et al., 2017). Mosher, Bakas, and Champion (2013) found that more than 50% of caregivers of patients with lung cancer experienced negative emotional effects. In addition, caregivers have jobs, children, and their own everyday household tasks to manage. In addition, they may feel isolated because of the lack of available time to socialize, exercise, and pursue hobbies when they most need support. All of these factors may negatively affect caregiver quality of life.

Two large meta-analyses of family caregiver intervention trials provide an overview of the types of interventions and their effects on caregiver outcomes. A meta-analysis by Northouse, Katapodi, Song, Zhang, and Mood (2010) listed the types of interventions primarily as psychoeducational, skills training, and therapeutic counseling. Interventions reduced caregiver burden, distress, and anxiety and improved coping, relationships, and physical functioning.