

Family Caregiver Strain and Burden

A systematic review of evidence-based interventions when caring for patients with cancer

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BACKGROUND: Caregivers of patients with cancer experience high levels of caregiver-related strain and burden (CGSB). Cancer caregiving is complex and can change dramatically depending on the cancer trajectory. Often, this experience leads to poor health outcomes for the caregiver.

OBJECTIVES: This review appraises the evidence on CGSB published from 2007 to October 2017.

METHODS: 128 interventional studies found in PubMed® and CINAHL® were appraised and categorized based on the Oncology Nursing Society's Putting Evidence Into Practice schema.

FINDINGS: Psychoeducation, supportive care/support interventions, and cognitive behavioral interventions are recommended to decrease CGSB. Caregiver skill training, couples therapy, decision support, mindfulness-based stress reduction, multicomponent interventions, and palliative care are likely to be effective. The evidence is not established for 13 interventions. Despite the proliferation of studies focusing on CGSB, studies with stronger designs and larger samples are needed.

KEYWORDS

family caregiver; caregiver strain and burden; evidence-based practice

DIGITAL OBJECT IDENTIFIER

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APPROXIMATELY 15.5 MILLION AMERICANS ARE LIVING WITH A HISTORY of cancer, and an estimated 1.76 million new cases were expected in 2019 (American Cancer Society, 2019). In recent years, increased attention has been given to family caregivers. Often, caregiving involves significant amounts of time and energy, and requires the performance of tasks that may be physically, emotionally, socially, or financially demanding. Although caregivers report many positive aspects of providing care, complex care is a stressor and leads to negative consequences that are referred to as caregiver strain and burden (National Alliance for Caregiving [NAC], 2016).

Caregiver strain and burden, terms used interchangeably in this article, is multidimensional in nature and encompasses difficulties in assuming and functioning in the caregiver role; caregiving is also associated with alterations in caregivers' emotional and physical health that can occur when care demands exceed resources (Oncology Nursing Society [ONS], 2017). Increased caregiving can negatively affect the patient and the caregiver. Forty-two percent of family caregivers perform skilled medical or nursing tasks for their loved ones, often with insufficient assistance or training from healthcare professionals (Mollica, Litzelman, Rowland, & Kent, 2017).

The NAC (2016), in collaboration with the National Cancer Institute and the Cancer Support Community, estimated the number of caregivers of patients with cancer at 3 million. The estimate was based on a nationally representative sample of adults; however, the authors cautioned that the actual percentage of cancer caregivers is likely higher because cancer may be a secondary condition for many older family members who require support. The cancer caregivers in the NAC (2016) report experienced episodic and intense caregiving, which was associated with high burden where they spent an average of 32.9 hours per week caring for their loved ones.

Caregivers of patients with cancer have a unique role compared to caregivers of patients with other chronic illnesses (Kim & Schulz, 2008). Their role and level of involvement can change quickly and dramatically depending on the nature of cancer. They are expected to respond to and monitor multiple disease symptoms and treatment modalities, in addition to the uncertainty that persists across the disease trajectory (Kent et al., 2016).