

Family Caregiver Preparedness: Developing an Educational Intervention for Symptom Management

Betty R. Ferrell, RN, PhD, MA, FAAN, FPCN®, CHPN®, Nora Ruel, MA, Tami Borneman, RN, MSN, CNS, FPCN®, Marianna Koczywas, MD, and Mihaela C. Cristea, MD

BACKGROUND: Family caregivers provide complex care for patients with cancer, including management of multiple symptoms associated with the disease and its treatment.

OBJECTIVES: The objective of this pilot project was to develop and conduct feasibility testing of a family caregiver educational intervention for symptom management.

METHODS: The intervention was conducted with 23 family caregivers of patients with lung or gynecologic cancer to evaluate feasibility testing and assessment of caregiver preparedness, quality of life, and psychological distress at baseline and three and seven weeks postintervention.

FINDINGS: Family caregivers were very interested in education related to their role in symptom management, with management of constipation, dyspnea, and diarrhea as the highest priorities. The intervention was feasible and valuable in assisting family caregivers in assessing symptoms and making decisions regarding treatment choices.

KEYWORDS

family caregiver; preparedness; symptom management; advanced cancer

DIGITAL OBJECT IDENTIFIER

10.1188/22.CJON.165-175

FAMILY CAREGIVERS OF PATIENTS WITH CANCER manage complex symptoms, including pain and neuropathy, dyspnea, skin changes or rash, diarrhea and constipation, and numerous other symptoms associated with the disease or its treatment. This pilot project builds on a National Academies of Sciences, Engineering, and Medicine (2016) report, which called for models of family caregiver support to be developed and widely disseminated. Prior research has focused primarily on emotional support for family caregivers, and there has been less focus on supporting caregivers in the areas of physical care, symptom management, or practical caregiving skills (Becqué et al., 2019; Chi & Demiris, 2017; Ferrell & Wittenberg, 2017; Keramatikerman, 2020). This is particularly significant because of the shift of patient care to the home and the burden of increased complexity of care, specifically for underserved or poor families.

There are about 53 million individuals in the United States who are providing unpaid support to someone affected by a serious or debilitating illness, such as cancer (AARP and National Alliance for Caregiving, 2020). Having serious illness often results in functional limitations, mental impairment, debilitating symptoms, and the need for complex medication regimens. The National Academies of Sciences, Engineering, and Medicine (2016) and organizational guidelines have stressed the importance of ensuring that family caregivers are kept healthy and functioning, particularly in the advanced stages of a family member's illness and during end-of-life care when patient care demands and caregiver burdens increase (Dionne-Odom et al., 2017; Hampton & Newcomb, 2018; Kent et al., 2016; Longacre et al., 2018; McFarlane & Liu, 2020; Ortega-Galán et al., 2019; Streck et al., 2020; Washington et al., 2021). In oncology, recent advances in diseases such as lung cancer have extended survival, thereby extending the time of family caregiving. Patients with cancer also often represent older ages, and family caregivers may include older spouses who can have major health concerns of their own.

In addition, there is a growing body of evidence regarding the financial burden of cancer (Altice et al., 2016; Davis & Fugett, 2018; National Cancer Institute, 2019; Tan et al., 2018; Zafar, 2016). Financial factors associated with cancer are numerous, including out-of-pocket expenses, lost work time, travel costs, medication copayments, insurance deductibles, over-the-counter medications, payment for services the patient or caregiver can no