

FOCUS Program

Treating patients with cancer and family caregivers as a unit of care

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BACKGROUND: Studies indicate that patients' and caregivers' responses to illness are interdependent; each person affects the other. Existing evidence reinforces the need to recognize family caregivers as equal recipients of care and support.

OBJECTIVES: This evidence-based pilot study evaluated the feasibility and preliminary efficacy of the nurse-guided, psychoeducational, family-based FOCUS program intervention at a local oncology outpatient clinic.

METHODS: 30 patient-caregiver dyads were recruited from a local oncology clinic. Intervention delivery occurred using home visits and telephone calls. Self-administered questionnaires were used to assess participants' self-efficacy, quality of life (QOL), and coping pre- and postintervention, and intervention satisfaction postintervention. Three tailored psychosocial education sessions were held during a 6- to 9-week period.

FINDINGS: Significant changes in outcomes were found, including increased self-efficacy in both patients and caregivers, higher QOL in caregivers, and decreased use of substances for coping in patients. There was a trend for patients' emotional well-being to improve over time; other aspects of QOL showed little change. There were no significant changes in caregivers' coping.

KEYWORDS

dyadic intervention; psychosocial education; quality of life; coping; self-efficacy

DIGITAL OBJECT IDENTIFIER

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CANCER CAN CAUSE MAJOR DISRUPTIONS IN THE LIVES of patients and their family caregivers. It is well established that patients with cancer and their caregivers react as an emotional system rather than as individuals (Litzelman & Yabroff, 2015). Caregivers require information and support, but often their needs are not addressed adequately during clinical visits. Underprepared and distressed caregivers may not be able to provide needed support and care, which could hinder the desired outcomes of cancer care and negatively affect the physical and mental health of patients (Litzelman et al., 2016). Studies indicate that when caregivers are depressed, patients are four times more likely to be depressed and three times more likely to receive lower quality of care at home (Litzelman et al., 2016; Litzelman & Yabroff, 2015). Conversely, when caregivers had a greater sense of mastery of their caregiving role, the patients they were caring for had better survival rates (Boele et al., 2017). Because caregivers' well-being affects patients' well-being, recognizing and supporting family caregivers as equal recipients of care is essential.

According to the National Cancer Institute (2020), about 16.9 million people were living with a cancer diagnosis in 2019. Estimates indicate that there will be about 22.2 million cancer survivors in the United States by 2030, suggesting a significant and growing population of people living with this chronic health condition. In addition to patients with cancer, caregivers need assistance to cope with the challenges associated with a cancer diagnosis and treatment. Some countries, such as Australia, Germany, and the United Kingdom, have successfully implemented national policies to support caregivers. However, the U.S. healthcare system focuses care primarily on the patient rather than the dyad (U.S. Government Accountability Office, 2020).

The American Cancer Society (2016) defines caregiver as "the person who most often helps the person with cancer and is not paid to do so. . . . Caregivers may be partners, family members, or close friends. Most often, they're not trained for the caregiver job" (p. 1). Research supports the interdependent relationship between patients and caregivers, and improved outcomes in quality of life (QOL) and coping with cancer are evident when dyad members work together to manage illness-related problems. In a large population-based study by Litzelman et al. (2016), dyadic interventions tended to have greater impact on improving couples' communication and relationship and on decreasing psychological distress than patient-only or caregiver-only interventions. In a meta-analysis by Hu et al. (2019), dyadic interventions were associated with significant improvements in patients' total QOL.

Evidence of the effectiveness of dyadic interventions exists (Ferrell & Wittenberg, 2017), but clinical implementation that treats patients and caregivers together as a unit is lacking, particularly in smaller oncology centers.