

# Family Caregiver Burden, Skills Preparedness, and Quality of Life in Non-Small Cell Lung Cancer

Marcia Grant, RN, PhD, FAAN, Virginia Sun, RN, PhD, Rebecca Fujinami, RN, BA, OCN<sup>®</sup>, CCM, Rupinder Sidhu, MSW, LCSW, Shirley Otis-Green, MSW, LCSW, ACSW, OSW-C, Gloria Juarez, RN, PhD, Linda Klein, JD, and Betty Ferrell, PhD, FAAN, MA, FPCN, CHPN

A cancer diagnosis profoundly impacts not only the patient but also the family. Family caregivers, along with patients, exist within a social unit that can be negatively impacted throughout the cancer continuum, from diagnosis to end of life (Ferrell & Mazanec, 2009; Given, Given, & Sherwood, 2012; Lewis, 2004). Caregivers, although profoundly impacted by a loved one's cancer diagnosis, have received only minimal attention by most healthcare providers who are focused primarily on the physical needs of the patient. The current literature recognizes the multidimensional needs of caregivers throughout the continuum of the cancer experience (Honea et al., 2008). The current article presents descriptive findings from the usual care phase of an National Cancer Institute (NCI)-funded Program Project Grant that aims to test the efficacy of an interdisciplinary palliative care intervention delivered by advanced practice nurses (APNs) for patients and families living with non-small cell lung cancer (NSCLC). The Lung Cancer Program Project Grant involves three intervention projects (early stage, late stage, family caregivers) and three cores (administrative, biostatistics, geriatrics) that, in conjunction, aim to address symptoms and quality of life (QOL) issues through the integration of palliative care. This article describes how data on caregiver burden, skills preparedness, psychological distress, and QOL informed the development of an interdisciplinary, tailored palliative care intervention to meet the physical, psychological, social, and spiritual needs of caregivers of patients with NSCLC. Caregivers are defined as a spouse, adult child, other relative, partner, or friend who has a personal relationship with and provides a broad range of unpaid assistance for an adult with a serious illness (Given, Sherwood, & Given, 2011).

## Literature Review

Patients with NSCLC have tremendous needs in areas such as symptom burden, mood disorders, and overall

**Purpose/Objectives:** To describe burden, skills preparedness, and quality of life (QOL) for caregivers of patients with non-small cell lung cancer (NSCLC), and describe how the findings informed the development of a caregiver palliative care intervention that aims to reduce caregiver burden, improve caregiving skills, and promote self-care.

**Design:** Descriptive, longitudinal.

**Setting:** A National Cancer Institute–designated comprehensive cancer center in southern California.

**Sample:** 163 family members or friends aged 18 years or older and identified by patients as being a caregiver.

**Methods:** All eligible caregivers were approached by advanced practice nurses during a regularly scheduled patient clinic visit. Informed consent was obtained prior to study participation. Outcome measures were completed at baseline and repeated at 7, 12, 18, and 24 weeks. Descriptive statistics were computed for all variables, and one-way repeated-measures analysis of variance was used to test for change over time for all predictor and outcome variables.

**Main Research Variables:** Caregiver burden, skills preparedness, psychological distress, and QOL.

**Findings:** Caregivers were highly functional. Caregiver burden related to subjective demands increased significantly over time. Perceived skills preparedness was high at baseline but decreased over time. Psychological distress was moderate but increased in the study period. Overall QOL was moderate at baseline and decreased significantly over time. Psychological well-being had the worst QOL score.

**Conclusions:** Caregivers experienced high levels of caregiver burden and reported deteriorations in psychological well-being and overall QOL.

**Implications for Nursing:** Oncology nurses need to ensure that caregivers receive information that supports the caregiving role throughout the cancer trajectory.

**Knowledge Translation:** Although family caregivers are profoundly impacted by a loved one's lung cancer diagnosis, the literature about caregiver burden, skills preparedness, and QOL is limited. Current evidence suggests that family caregivers can be negatively impacted by a loved one's cancer diagnosis. Caregiver-specific support interventions are needed to eliminate the burden of caregiving in lung cancer.