

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

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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.

QOL deficits, a fact that is well established in the current literature (Brant et al., 2011; Brown, Cooley, Chernecky, & Sarna, 2011; Cleeland et al., 2011; Ferrell, Koczywas, Grannis, & Harrington, 2011; Floyd et al., 2011; Lee et al., 2011; Prasertsri, Holden, Keefe, & Wilkie, 2011; Vos, Putter, van Houwelingen, & de Haes, 2011). The caregiving role in cancer, particularly for those caring for a family member or friend with NSCLC, can be associated with physical, psychological, social, functional, and spiritual burden for informal caregivers. Montgomery, Gonyea, and Hooyman (1985) defined caregiver burden as the distress that caregivers feel as a result of providing care; this distress is different from depression, anxiety, and other emotional responses (Ferrell & Mazanec, 2009). Caregiver burden is influenced by characteristics of the patient, caregivers, and the care environment. Patient characteristics, including diagnosis, treatment, stage of disease, and amount of caregiving-related tasks, have been shown to influence caregiver burden (Ferrell & Mazanec, 2009; Given et al., 2011; Hwang et al., 2003; Sharpe, Butow, Smith, McConnell, & Clarke, 2004). Caregivers who are older, have distressed relationships with patients, and have little social support report higher levels of caregiver burden (Ferrell & Mazanec, 2009; Gaugler et al., 2005; Nijboer, Tempelaar, Triemstra, van den Bos, & Sanderman, 2001). Certain characteristics of the care environment, including socioeconomic status and the type of caregiving tasks, also may impact perceived caregiver burden (Ferrell & Mazanec, 2009; Sharpe et al., 2004; Spillers, Wellisch, Kim, Matthews, & Baker, 2008; Stenberg, Ruland, & Miaskowski, 2010; van Ryn et al., 2011; Williams & McCorkle, 2011).

Caregivers of patients with lung cancer are required to manage multiple patient symptoms, such as dyspnea, pain, and fatigue. Caregivers also are responsible for dealing with the patient's nutrition needs in situations where the patient experienced significant functional declines that affect patients' ability to perform activities of daily living (Ferrell & Mazanec, 2009; van Houtven, Ramsey, Hornbrook, Atienza, & van Ryn, 2010; van Ryn et al., 2011). Caregiving also involves the psychological burdens of coping with the patient's anxiety and depression (Bakas, Lewis, & Parsons, 2001; Ferrell & Mazanec, 2009). Added to these intense demands is the reality of lung cancer as a disease with frequent recurrence in early-stage disease and death in late-stage disease (Gridelli et al., 2007; Ryan, Howell, Jones, & Hardy, 2008).

Caregivers of patients with cancer often are expected to have already obtained certain caregiving skills (Ferrell & Mazanec, 2009). Physical care for people with lung cancer may include helping with ambulation, moving or lifting patients, assistance with nutritional management, and managing common symptoms (Bakas et al., 2001; Ferrell & Mazanec, 2009). Too often, caregivers are expected to perform those complex tasks

**Table 1. Caregiver Characteristics (N = 163)**

Characteristic	$\bar{X}$	Range
Age (years)	57.23	21–88
Characteristic	n	%
<b>Race</b>		
White	115	71
Asian	25	15
Black or African American	7	4
American Indian or Alaska Native	2	1
Native Hawaiian or other Pacific Islander	1	< 1
More than one race	10	6
Unknown or unreported	3	1
<b>Ethnicity: Hispanic or Latino</b>		
No	146	90
Yes	17	10
<b>Gender</b>		
Female	105	64
Male	58	36
<b>Relationship with patient</b>		
Spouse or partner	111	68
Daughter	26	16
Son	7	4
Parent	4	3
Other	15	9
<b>Living situation<sup>a</sup></b>		
Spouse or partner	135	83
Children (aged 18 years or younger)	21	13
Children (aged 19 years or older)	19	12
Parent(s) or parent(s)-in-law	12	7
Other relative	10	6
Live alone	6	4
Other	2	1
<b>Education</b>		
Elementary school	2	1
Secondary or high school	61	37
College	100	61
<b>Marital status</b>		
Married or partnered	133	82
Single	16	10
Divorced	11	7
Separated	1	< 1
Widowed	1	< 1
No response	1	< 1
<b>Employment status<sup>a</sup></b>		
Employed more than 32 hours per week	56	34
Retired	52	32
Employed less than 32 hours per week	17	10
Unemployed	17	10
Homemaker	14	9
Disabled	5	3
Full-time student	1	< 1
Other	14	9
<b>Income (\$)</b>		
10,000 or less	6	4
10,001–20,000	7	4
20,001–30,000	6	4
30,001–40,000	11	7
40,001–50,000	9	6
More than 50,000	92	56
Prefer not to answer	32	20

(Continued on the next page)

<sup>a</sup> Participants could choose more than one response.

Note. Because of rounding, percentages may not total 100.

**Table 1. Caregiver Characteristics (N = 163)  
(Continued)**

Characteristic	n	%
<b>Do you have a primary doctor?</b>		
Yes	138	85
No	25	15
<b>Smoking history</b>		
Nonsmoker	86	53
Former smoker	63	39
Current smoker	14	9
<b>Comorbidities (N = 102)</b>		
Cardiovascular	62	61
Endocrine or metabolic	36	35
Musculoskeletal	34	33
Anxiety or depression	30	29
Respiratory	15	15
Stomach or gastrointestinal disorders	14	14
Cancer	9	9
Other	21	21

<sup>a</sup> Participants could choose more than one response.

Note. Because of rounding, percentages may not total 100.

alone, without any formal assessment of their level of efficacy related to caregiving or formal support (Ferrell & Mazanec, 2009). The current literature suggests that caregivers' perceived skills preparedness is associated with caregiver burden. In a study with 59 caregivers, Scherbring (2002) reported that higher caregiver burden and lower caregiver QOL were associated with perceived preparedness for the caregiving role.

An emerging body of evidence suggests that caregivers also derive benefits from their caregiving role. Domains of benefit finding in cancer caregiving have been described in the literature, and include acceptance, empathy, appreciation, family, positive self-view, and reprioritization (Kim, Schulz, & Carver, 2007). In hospice settings, spousal caregivers who were able to find meaning and subjective benefits from caregiving were less likely to be depressed and also reported having higher life satisfaction (Haley, LaMonde, Han, Burton, & Schonwetter, 2003).

The cancer experience can still profoundly affect caregivers' QOL (Kim, Baker, & Spillers, 2007; Kim & Given, 2008; Kim & Spillers, 2010). Research indicates that as patients' disease progresses, the physical well-being of caregivers decreases (Corà, Partinico, Munafò, & Palomba, 2012; Given et al., 2011; Harding, List, Epiphaniou, & Jones, 2012; Ji, Zöller, Sundquist, & Sundquist, 2012; Williams & McCorkle, 2011). An emerging body of literature suggests that higher caregiver burden is associated with increased mortality risk for caregivers (Braun, Mikulincer, Rydall, Walsh, & Rodin, 2007; Corà et al., 2012; Ji et al., 2012). Psychological demands of caregiving, such as anxiety, depression, and psychological distress, are common in caregivers of patients with lung cancer (Chambers et al., 2012; Murray et al., 2010;

Ostlund, Wennman-Larsen, Persson, Gustavsson, & Wengström, 2010; Rivera, 2009; Roth, Perkins, Wadley, Temple, & Haley, 2009; Siminoff, Wilson-Genderson, & Baker, 2010). The social demands of caregiving are related primarily to relationships, social support, and financial factors. Marital relationships and family communication patterns can be strained, and research has revealed that depression in both the patient and spouse negatively affected marital relationships (Hagedoorn, Sanderman, Bolks, Tuinstra, & Coyne, 2008; Kim, Carver, Deci, & Kasser, 2008; Lindau, Surawska, Paice, & Baron, 2011; Manne, Badr, & Kashy, 2011). Research suggests that caregivers, similar to patients with cancer, often experience spiritual distress but also derive meaning in their cancer caregiving experience (Colgrove, Kim, & Thompson, 2007; Kim, Carver, Spillers, Crammer, & Zhou, 2011; Kim, Wellisch, Spillers, & Crammer, 2007).

Research has focused on the development and testing of interventions to support cancer caregivers. A meta-analysis conducted by Northouse, Katapodi, Song, Zhang, and Mood (2010) found that psychoeducational, skills training, and therapeutic counseling interventions were predominant methods used in the caregiver intervention literature. They found that most interventions were delivered in a dyadic fashion, but dose and duration varied tremendously across studies. The interventions were found to have small to medium effects on reducing caregiver burden, improving caregiver coping, increasing caregiver self-efficacy, and improving aspects of caregiver QOL (Northouse et al., 2010). That meta-analysis provided crucial evidence to guide researchers in the development of effective caregiver interventions.

The current literature supports the significant burden of caregiving and the limited research on lung cancer caregiving. Given the burdens of the healthcare system, the chronically ill, and the United States' aging population, caregiving increasingly is recognized as a major public health concern. The intense psychological impact of a lung cancer diagnosis is matched by the practical demands and physical care assumed by caregivers. A need exists to develop evidence-based supportive care models for caregivers of patients with lung cancer. Understanding caregiver burden, skills preparedness, and QOL is a first step to designing scientifically sound nursing interventions to support the caregiving role for patients with lung cancer.

## Methods

### Sample and Setting

Caregivers were recruited from the medical oncology adult ambulatory care clinic at City of Hope National Medical Center, an NCI-designated comprehensive cancer center in Duarte, CA. Family members or friends

aged 18 years or older and identified by patients with NSCLC as being the caregiver were eligible for study participation. Eligible caregivers were recruited to assess usual care in phase 1 of this two-phase Program Project Grant. A total of 163 caregivers were accrued and were eligible for analysis (consented with baseline data).

## Procedures

The study protocol was approved by City of Hope's institutional review board prior to study initiation. All eligible caregivers were approached by APNs during a regularly scheduled patient clinic visit. Written informed consent was obtained from all caregivers prior to study participation, and caregivers were recruited consecutively. Following informed consent, caregivers completed baseline assessment that included basic demographic information as well as outcome measures to assess functional status, caregiver burden, skills preparedness, psychological distress, overall QOL, and caregiver resource use. The measures were administered either verbally or through caregivers' written responses, and they were repeated at 7, 12, 18, and 24 weeks following accrual.

## Instruments

Basic caregiver demographics were obtained at baseline for the following variables: age, race or ethnicity, gender, relationship to patient, living situation (i.e., whether the caregiver lived with the patient and other members of the household), education, marital status, employment, income, access to primary healthcare, smoking history, and comorbidities.

Caregiver functional status was assessed using the **Instrumental Activities of Daily Living (IADL)** subscale of the **Older American Resources and Services (OARS)**. The IADL subscale consists of seven questions rated on a Likert-type scale, ranging from 1 (without help) to 3 (unable to perform activity), assessing the degree to which the activity can be performed independently. The **OARS Multidimensional Functional Assessment**

**Questionnaire (OMFAQ)** was developed to provide a profile of the level of functioning and need for services of older adults who live at home but may have some degree of impairment. The OMFAQ has been tested on more than 6,000 older community residents (Fillenbaum & Smyer, 1981). Norms are available for the OMFAQ based on 2,146 older adult community residents (George & Fillenbaum, 1985). Correlational coefficients ranged from 0.66–0.87.

Caregiver burden was assessed using the **Caregiver Burden Scale**, a 14-item survey that measures the impact of caregiving on three dimensions of burden: objective, subjective demand, and subjective stress (Montgomery, Gonyea, et al., 1985; Montgomery, Stull, & Borgatta, 1985). Objective burden is defined as the perceived interruption of the tangible aspects of a caregiver's life (Ferrell & Mazanec, 2009). Subjective demand burden is the caregiver's perceived demands of caregiving responsibilities (Ferrell & Mazanec, 2009). Subjective stress burden is the caregiver's perceived emotional response to the caregiving responsibilities (Ferrell & Mazanec, 2009; Montgomery, Gonyea, et al., 1985). The ordinal scale ranges from 1 (a lot less) to 5 (a lot more). Internal consistency for the three dimensions ranges from 0.82–0.88 (Montgomery, Stull, et al., 1985). Cutoff scores were established for each of the burden dimensions, with objective burden scores of greater than 23, subjective demand scores of greater than 15, and subjective stress scores of greater than 13.5 indicating higher levels of burden (Montgomery, Stull, et al., 1985).

Caregiver skills preparedness was assessed using Archbold, Stewart, Greenlick, and Harvath's (1990) **Preparedness for Caregiving Scale**. The measure is an eight-item scale of the Family Care Inventory. Preparedness is defined as the perceived readiness for multiple domains of the caregiving role, such as providing physical care, offering emotional support, setting up in-home support services, and dealing with the stress of caregiving. Items address caregivers' comfort with various physical and emotional patient needs and are scored from 0 (not at all prepared) to 4 (very well prepared). Internal consistency ranges from 0.88–0.93 (Archbold et al., 1990; Schumacher, Stewart, & Archbold, 2007).

Caregiver psychological distress was measured with the **Psychological Distress Thermometer**. The measure is an efficient method with low subject burden recommended by the National Comprehensive Cancer Network's Distress Management Guidelines to evaluate psychological distress during the past week based on a scale of 0 (no distress) to 10 (extremely distressed). A score of 5 or higher indicates a need for intervention (Graves et al., 2007). Analyses of Distress Thermometer scores indicated good overall accuracy compared to the Hospital Anxiety and Depression Scale (0.8) and Brief Symptom Inventory (0.78).

**Table 2. Family Caregiver Response to Instrumental Activities of Daily Living Subscale (N = 163)**

Question	$\bar{X}$	SD
<b>Can you . . .</b>		
Use the telephone?	2	0
Get to places out of walking distance?	1.94	0.241
Shop for groceries or clothes?	1.96	0.189
Prepare your own meals?	1.95	0.217
Do your housework?	1.9	0.298
Take your own medicine?	1.98	0.135
Handle your own money?	1.98	0.135
<b>Overall score</b>	13.79	0.769

Note. Scores based on a 1–3 scale where 1 = without help, 2 = with some help, and 3 = unable to perform activity.

**Table 3. Family Caregiver Outcome Measures**

Variable	Baseline		Week 7		Week 12		Week 18		Week 24		p
	$\bar{X}$	SD	$\bar{X}$	SD	$\bar{X}$	SD	$\bar{X}$	SD	$\bar{X}$	SD	
Caregiver objective burden (score greater than 23 = higher burden)	15.84	7.63	15.95	7.57	16.3	8.05	14.34	8.22	14.4	8.56	0.001
Caregiver subjective demand (score greater than 15 = higher burden)	10.79	3.55	10.83	3.76	11.41	3.44	11.43	3.17	11.25	3.38	0.021
Caregiver subjective stress (score greater than 13.5 = higher burden)	14.17	3.22	13.87	3	13.76	3.12	13.72	2.77	13.73	2.7	0.293
Caregiver skills preparedness (0–4 scale; higher score = more prepared)	3.72	0.777	3.52	0.758	3.56	0.768	3.49	0.755	3.54	0.761	0.000
Psychological distress (0 = no distress; 10 = extremely distressed)	4.41	2.81	4.57	2.95	4.68	2.94	4.67	2.7	4.84	2.66	0.332
Physical well-being <sup>a</sup>	7.54	1.98	7.37	1.86	7.26	1.82	6.93	2.01	6.97	2.04	0.000
Psychological well-being <sup>a</sup>	5.43	1.73	5.32	1.73	5.25	1.71	5.17	1.64	5.12	1.66	0.007
Social well-being <sup>a</sup>	6.7	1.89	6.16	2.02	6.02	1.95	6.09	1.81	6.02	1.91	0.000
Spiritual well-being <sup>a</sup>	6.49	2.02	6.75	1.86	6.63	1.87	6.61	1.76	6.37	2	0.007
Total quality of life <sup>a</sup>	6.24	1.52	6.1	1.52	5.99	1.5	5.03	1.46	5.84	1.55	0.000

<sup>a</sup>Scores range on a scale from 0–10, with higher scores indicating better quality of life.

Caregiver QOL was assessed using the **City of Hope QOL Scale–Family Version**. The 37-item ordinal instrument measures the QOL of a family member caring for a patient with cancer. Four QOL domains are measured: physical, psychological, social, and spiritual well-being. The ordinal scale ranges from 1–10, with higher scores indicating worse QOL. The instrument was revised and tested from 1994–1998 in a study of 219 caregivers of patients with cancer. The test-retest reliability was 0.89 and internal consistency (alpha) was 0.69. Factor analysis confirmed the four QOL domains as subscales for the instrument (Ferrell, Ferrell, Rhiner, & Grant, 1991; Ferrell, Grant, Borneman, Juarez, & ter Veer, 1999; Ferrell, Grant, Chan, Ahn, & Ferrell, 1995).

Finally, caregiver resource use was assessed through caregiver self-report at all follow-up time points to determine the type of resources caregivers accessed. Specific categories were created by the investigators, including physical, emotional, and spiritual support.

### Data Analysis

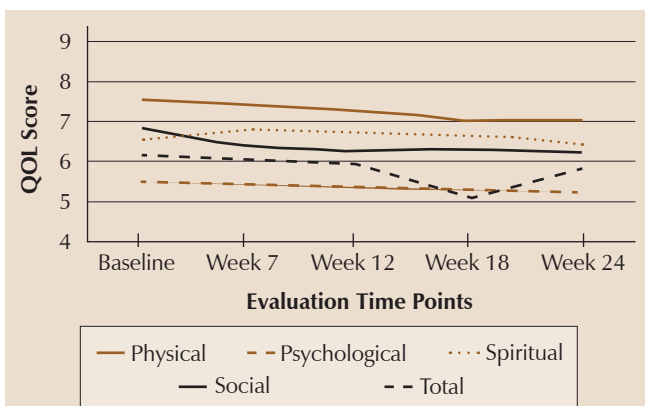
Scannable data forms developed using the Remark system (a program that aids in the development of scannable surveys) were completed by APNs and caregivers. Data were scanned, audited for accuracy, and read into an SPSS®, version 19, system file. Missing values analysis revealed that values were missing completely at random, allowing for imputation using

the estimation-maximization method. 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.

### Results

Basic caregiver demographic data are presented in Table 1. No demographic differences were found between completers and noncompleters. Predominant comorbidities included cardiovascular, endocrine or metabolic, and musculoskeletal issues, as well as anxiety or depression. Caregivers were highly functional in instrumental activities of daily living (see Table 2).

Table 3 presents findings for all outcome measures assessed in the study. For caregiver burden, caregivers experienced high levels of subjective stress, with mean scores being higher than the cutoff score of 13.5 across all follow-up time points. Subjective stress also was stable throughout all measurement periods. Objective burden changed significantly across time, peaking at 12 weeks and then significantly decreasing. Subjective demand increased significantly for 7, 12, and 18 weeks and then began to decrease. Caregivers' perceived skills preparedness was high at baseline, but decreased over time—that difference was statistically significant. Psychological distress was moderate throughout the



Note. Scale ranges from 1–10, with higher scores indicating better QOL.

**Figure 1. Family Caregivers' Quality of Life (QOL) Changes Over Time (N = 163)**

five measurement periods, but increased over time, although the difference was not statistically significant.

Figure 1 depicts QOL changes across the five follow-up time points. At baseline, overall QOL was moderate and decreased significantly over time. Scores for the four QOL domains also decreased significantly over time. Of the four QOL domains, psychological well-being had the worst score, followed by social, spiritual, and physical well-being, respectively.

Table 4 presents findings on individual items for caregiver outcome measures. Items with a score greater than 3.7 (1–5 scale, where higher scores indicate greater burden) were selected for the Caregiver Burden Scale. Caregivers reported higher burden for items such as time for self, personal privacy, time for recreation, tension in life, vacation and trips, time for own work and chores, and time for friends or relatives. For QOL (City of Hope QOL Scale–Family Version), items with a score of less than 5 (0–10 scale, where lower scores indicate worse QOL) were selected, and they included primarily psychological well-being issues such as distress of initial diagnosis, treatment, anxiety, fear of recurrence, overall family distress, and uncertainty.

Findings related to caregiver resource use are depicted in Figure 2. The most commonly used source of support was talking to family and friends (96%–99% over time), followed by help from family and/or neighbors, cleaning services, spiritual counseling, home health services, support groups for caregivers, social work, and professional counseling. The type of resources used did not change over time.

## Discussion

Findings from this usual care phase of a Lung Cancer Program Project Grant demonstrated that high caregiver

burden and low QOL were common in caregivers of a loved one with NSCLC. That finding supports previous studies conducted specifically with caregivers of patients with lung cancer, which showed that perceived caregiver burden is high and QOL diminished (Murray et al., 2010; Persson, Ostlund, Wennman-Larsen, Wengström, & Gustavsson, 2008; van Houtven et al., 2010). For the three burden dimensions, results suggest that caregivers experienced high levels of perceived subjective stress, indicating that the emotional impact of caregiving responsibilities on the caregiver was burdensome. The fact that significant changes were not seen in the scores across time for that dimension suggests that the high level of emotional stress remained constant. Although scores for the other two burden dimensions (objective demand and subjective demand) were not high according to established cutoffs, the statistically significant increase in the subjective demand scores over time suggest that the extent to which the caregiver's care responsibilities are perceived to be overly demanding progressively increased. Previous studies, although not specific to lung cancer, have shown that as patients progress through treatment and as their medical conditions worsen, caregiving demands increase as well (Roth et al., 2009; Schumacher et al., 2008).

Studies focusing on informal cancer caregiving have shown that assuming caregiving responsibilities has a negative impact on caregivers' overall QOL (Bergelt, Koch, & Petersen, 2008; Kitrungröter & Cohen, 2006; Mancini et al., 2011). Results from the current study support previous findings. Total QOL scores and the four QOL subscale scores all decreased significantly over time. The current study's findings also suggest that psychological QOL was the worst across all four domains. Because psychological well-being focuses on assessing emotional issues such as anxiety and depression, the data suggest that these are important areas to address for caregivers. Emotional strain and depressive symptoms are common in cancer caregivers, and have been documented specifically in lung cancer settings as well (Siminoff et al., 2010). In terms of overall QOL, a significant drop in overall QOL scores was observed between the 12- and 18-week follow-up points, followed by a significant recovery of scores between the 18- and 24-week time points. With this planned analysis, the authors were unable to determine the specific cause of those precipitous changes, but hypothesize that they may be related to fluctuations in patient conditions. Although the study's findings were specific to caregivers of patients with NSCLC, they also may be generalizable to other cancer types, as similar findings have been described in the current cancer caregiver literature across various cancer types (Given et al., 2011, 2012; Kim, Baker, Spillers, & Wellisch, 2006; Kim et al., 2011; Kitrungröter & Cohen, 2006).

**Table 4. Family Caregiver Outcomes—Items Ratings (N = 163)**

Question	Baseline			Week 7			Week 12			Week 18			Week 24		
	n	$\bar{X}$	SD	n	$\bar{X}$	SD	n	$\bar{X}$	SD	n	$\bar{X}$	SD	n	$\bar{X}$	SD
<b>Caregiver Burden Scale<sup>a</sup></b>															
Time for self	117	4.15	0.925	99	4.13	0.888	93	3.98	0.944	73	3.89	1.1	69	3.87	1.12
Personal privacy	70	4.06	1.05	59	4.03	0.809	60	3.97	0.991	46	3.91	0.985	46	3.85	1.01
Time for recreation	112	4.05	1.09	98	4.22	0.856	85	4.01	1.04	76	4.07	0.971	71	3.99	1.05
Tension in your life?	163	3.93	0.937	144	3.76	0.924	131	3.68	0.987	120	3.69	0.877	122	3.64	0.891
Vacation and trips	106	4.11	1.14	102	4.35	0.971	99	4.14	1.13	83	4.17	1.08	78	3.92	1.21
Time for own work and chores	93	3.96	0.999	76	4	0.8	75	3.83	1.08	55	3.82	0.945	60	3.97	0.882
Time for friends or relatives	102	3.87	1.21	78	4	0.926	79	3.94	1	69	3.8	1.08	66	3.85	1.14
<b>City of Hope QOL Scale—Family Version<sup>b</sup></b>															
Distress of patient's initial diagnosis	155	1.2	2.05	138	1.55	2.16	123	1.42	1.92	115	1.33	1.62	117	1.61	2.28
Distress of patient's treatment	140	3.51	3.39	123	3.5	3.1	117	3.29	2.83	109	3.03	2.61	113	3.01	2.7
Anxiety	133	4.85	3.05	112	5.07	2.95	106	5.06	2.9	101	4.86	2.58	101	4.61	2.73
Fear of second cancer in patient	140	3.79	3.82	128	3.68	3.56	116	4.11	3.59	104	3.45	3.37	105	3.51	3.24
Fear of recurrence in patient	145	3.14	3.66	129	3.12	3.44	118	3.56	3.46	107	3.07	3.22	111	3.26	3.24
Fear of metastasis in patient	148	2.82	3.55	131	3.05	3.4	119	3.52	3.53	105	2.55	3.09	111	2.63	3
Family distress	143	2.74	2.54	143	2.74	2.54	143	2.74	2.54	143	2.74	2.54	143	2.74	2.54
Rate your overall social well-being	163	6.94	2.03	144	6.69	2.14	132	6.6	2.03	120	6.64	1.82	122	6.67	2.06
Uncertainty	133	3.5	3.33	120	3.93	3.3	112	3.91	3.13	106	3.69	2.96	113	3.45	3.1

<sup>a</sup> Items with scores greater than 3.7

<sup>b</sup> Items with scores less than 5

QOL—quality of life

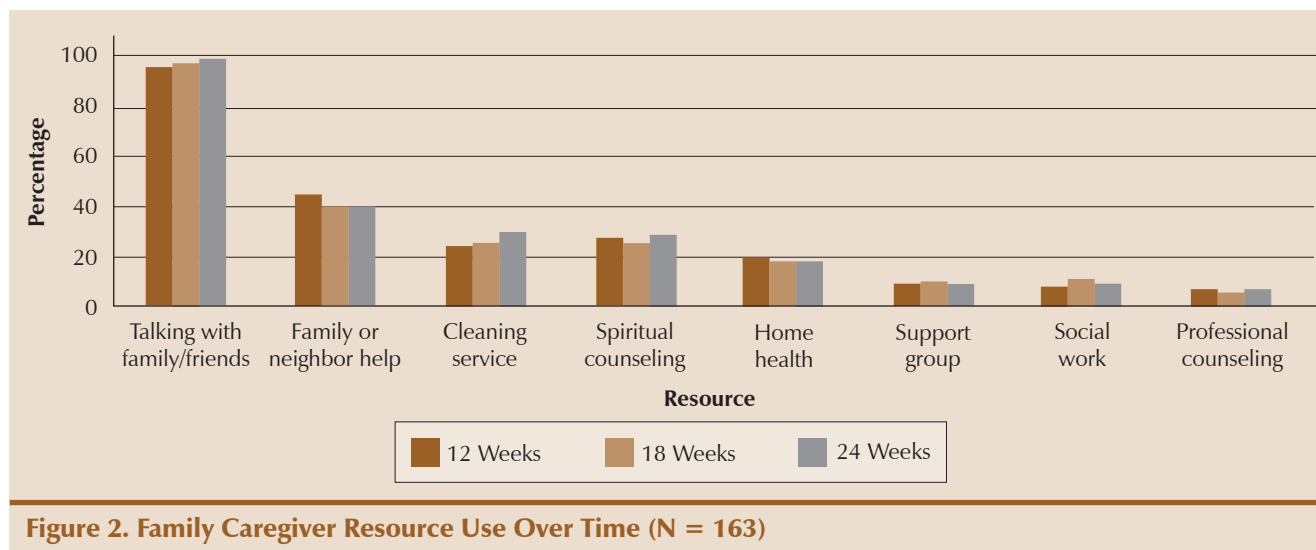
## Limitations

Study limitations included the inclusion of caregivers of patients with all stages of NSCLC, which may have confounded study findings. Although, as previously stated, similar findings in the current cancer caregiver literature have been described, the current study's findings may not be generalizable across other cancer types and in other settings. Even so, the findings confirmed other research in the current cancer caregiver literature, and also informed the development of an ongoing caregiver palliative care intervention.

## Intervention Development

Based on the study findings, an interdisciplinary palliative care intervention for caregivers in NSCLC was developed and is currently being tested at City of Hope. The overall purpose of phase 2 (experimental phase) of this Program Project Grant is to implement and test a palliative care intervention for caregivers of patients with NSCLC. Based on findings from the current study, the caregiver intervention included content addressing caregiver burden, with specific emphasis on coping with the emotional impact of caregiving. Content about skills preparedness focuses on providing skills education, as well as emphasizing the potential of new skills to be acquired as the patient's physical status changes. Finally, the intervention included a comprehensive self-care program for caregivers that addressed their own physical, emotional, social, and spiritual needs.

The intervention begins with the collection of baseline information using the same tools used in phase 1. Results of that evaluation are presented at an interdisciplinary care conference (ICC), where discussion of the comprehensive assessment of both the patient and caregiver are presented. Members of the ICC team include the treating oncologist or surgeon, nurse, and key supportive care experts (e.g., social work, nutrition, pulmonary and physical rehabilitation, pain and palliative medicine, spiritual, psychology). The ICC's focus is on interdisciplinary support of the patient's and caregiver's physical, psychological, social, and spiritual well-being. The interdisciplinary team makes



**Figure 2. Family Caregiver Resource Use Over Time (N = 163)**

palliative care–related recommendations for the patient and caregiver, which all are documented in a customized care plan. The care plan for caregivers focuses on two primary areas—the patient’s supportive care needs that the caregiver may need help addressing, and the caregiver’s self-care. Self-care includes healthy living recommendations, exercise, nutrition, managing the caregiver’s own health, and external support. Referrals to supportive care services also are initiated based on recommendations. Follow-up evaluations for the caregiver are conducted, and the care plan is revised periodically based on patient condition and caregiver needs. The caregivers receive educational materials and participate in four educational sessions. The session contents are divided into the four QOL domains (physical, psychological, social, spiritual well-being) and are focused on addressing caregiver burden, improving caregiving skills, and developing a caregiver self-care plan. This phase of the study will continue for two years.

## Implications for Nursing

Given the high levels of burden that caregivers experience, a critical need exists to develop and implement interventions to support the caregiving role for caregivers of patients with lung cancer. Most importantly, healthcare professionals, including oncology nurses, need to ensure that caregivers receive the appropriate resources and support to care for their loved ones at home. Palliative care has emerged as a viable model to effectively incorporate the needs of the patient and family through the use of a comprehensive and interdisciplinary approach to cancer care. Palliative cancer care has been defined as the “integration into cancer care of therapies that address multiple issues that cause suffering for patients and their families and impact their life quality” (Ferris et al., 2009, p. 3,052). National guidelines have been developed by

key organizations such as the National Comprehensive Cancer Network (2013) and the National Consensus Project (2009), and these guidelines recommend incorporating support for family members as an integral part of palliative care. Oncology nurses should be aware of the contents and recommendations of those guidelines that can aid in improving support for caregivers in cancer.

Given et al. (2012) presented a model of comprehensive caregiver assessment that can aid in identifying specific areas of needs and assist with selecting the appropriate resources and interventions during the caregiving journey. Areas for assessment included (a) caregivers’ competing demands, (b) living arrangements, (c) caregivers’ employment status, (d) financial needs, (e) demands in the level of care and time needed to provide that care, (f) caregivers’ knowledge and skills related to caregiving, (g) caregivers’ capacity and willingness to care, (h) caregivers’ own physical and mental health needs, (i) available social and family resources, and (j) caregivers’ expectations of the caregiving role (Given et al., 2012). Oncology nurses could use these valuable recommendations on conducting a comprehensive caregiver assessment and reassess if the patient’s situation and medical condition changes.

## Conclusion

The results of this study suggest that caregivers experience high levels of emotional stress related to the caregiving role and report deteriorations in psychological well-being and overall QOL over time while caring for a loved one with NSCLC. Those findings guided the development of a caregiver palliative care intervention that aims to improve caregiver outcomes. The design of the study allowed for a comprehensive assessment of perceived burden, skills preparedness, and QOL needs over time. Comprehensive QOL assessment and interdisciplinary



collaborations that focus on supporting psychological well-being and addressing the emotional stress related to the caregiving role may be key to improving the quality of comprehensive care for caregivers in cancer.

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