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

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Abstract

Purpose/Objectives—Describe burden, skills preparedness, and QOL for caregivers of patients with NSCLC, and describe how 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—One NCI-designated comprehensive cancer center in Southern California.

Sample—A total of 163 family members or friends who were 18 years or older and identified by patients as being the caregiver were accrued.

Methods—All eligible caregivers were approached by advance practice nurses (APNs) 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 (ANOVA) 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 over time. 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 report deteriorations in psychological well-being and overall QOL over time.

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

Introduction

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 (B. 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 upon 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). This article presents descriptive findings from the usual care phase of an NCI-funded Program Project Grant that aims to test the efficacy of an interdisciplinary palliative care intervention delivered by 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, aims 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

It is well-established in the current literature that patients with NSCLC have tremendous needs in areas such as symptom burden, mood disorders, and overall QOL deficits. (Akin, Can, Aydinler, Ozdilli, & Durna, 2010; Brant et al., 2011; Brown, Cooley, Chernenky, & Sarna, 2011; Cleeland et al., 2011; B. Ferrell, Koczywas, Grannis, & Harrington, 2011; Floyd et al., 2011; Lee et al., 2011; Lynch, Goodhart, Saunders, & O'Connor, 2011; Prasertsri, Holden, Keefe, & Wilkie, 2011; Sanders, Bantum, Owen, Thornton, & Stanton, 2010; Tishelman, Lovgren, Broberger, Hamberg, & Sprangers, 2010; Vos, Putter, van Houwelingen, & de Haes, 2011; Wang et al., 2010). 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 and colleagues defined caregiver burden as the distress that caregivers feel as a result of providing care, and this distress is different from depression, anxiety, and other emotional responses (B. Ferrell & Mazanec, 2009; Montgomery, Gonyea, & Hooyman, 1985b). 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 (B. 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 (B. 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, may also impact perceived caregiver burden (B. 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 lung cancer patients are required to manage multiple patient symptoms, such as dyspnea, pain, and fatigue. Caregivers are also responsible for dealing with the patient's nutrition needs in situations where the patient experienced significant functional declines (B. 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; B. 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).

Cancer caregivers are often expected to have already obtained certain caregiving skills (B. 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; B. Ferrell & Mazanec, 2009). Too often, caregivers are expected to perform these complex tasks alone, without any formal assessment of their level of efficacy related to caregiving or formal support (B. Ferrell & Mazanec, 2009). The current literature suggests that caregivers' perceived skills preparedness is associated with caregiver burden. In a study with 59 caregivers, Scherbring and colleagues reported higher caregiver burden and lower caregiver QOL was associated with perceived preparedness for the caregiving role. (B. Ferrell & Mazanec, 2009; Scherbring, 2002).

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 includes 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 report having higher life satisfaction (Haley, LaMonde, Han, Burton, & Schonwetter, 2003).

Nevertheless, 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 also decreases (Blum & Sherman, 2010; Cora, Partinico, Munafo, & Palomba, 2012; Given et al., 2011; Harding, List, Epiphaniou, & Jones, 2012; Ji, Zoller, Sundquist, & Sundquist, 2012; Northfield & Nebauer, 2010; Stenberg et al., 2010; 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; Cora et al., 2012; Ji et al., 2012). Psychological demands of caregiving, such as anxiety, depression, and psychological distress, are common in caregivers of lung cancer patients (Chambers et al., 2012; Murray et al., 2010; Östlund, 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 primarily related to relationships, social support, and financial factors. Marital relationships and family communication patterns can be strained, and research has revealed that depression in both patient and spouse negatively affected marital relationships (Badr & Taylor, 2006; Hagedoorn, Sanderman, Bolks, Tuinstra, & Coyne, 2008; Kim & Carver, 2007; Kim, Carver, Deci, & Kasser, 2008; Kim, Kashy, & Evans, 2007; Lindau, Surawska, Paice, & Baron, 2011; Manne, Badr, & Kashy, 2011; Sherwood et al., 2008). Spiritually, research suggests that similar to cancer patients, caregivers 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).

Over the years, an emerging body of evidence have focused on the development and testing of interventions to support cancer caregivers. A recent meta-analysis conducted by Northouse and colleagues found that psychoeducational, skills training, and therapeutic counseling interventions were predominant methods used in the caregiver intervention literature (Northouse, Katapodi, Song, Zhang, & Mood, 2010). 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). This meta-analysis provides 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 our aging population, caregiving is increasingly 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. There is a need 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 an NCI-designated comprehensive cancer center in Southern California. Family members or friends who were 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. The Lung Cancer Program Project Grant involves the synergistic implementation of three intervention projects (Early Stage, Late Stage, Family Caregiver) to integrate palliative care into comprehensive NSCLC care. A total of 163 caregivers were accrued and were eligible for analysis (consented with baseline data).

Procedures

The study protocol was approved by the Cancer Center's Institutional Review Board (IRB) 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 demographics as well as outcome measures to assess functional status, caregiver burden, skills preparedness, psychological distress, overall QOL, and caregiver resource utilization. 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/ethnicity, gender, relationship to patient, living situation (whether the caregiver lived with the patients and other members of the household), education, marital status, employment, income, access to primary healthcare, smoking history, and co-morbidities.

Caregiver functional status was assessed using the Instrumental Activities of Daily Living (IADL) subscale of the Older American Resources and Services (OARS). The OARS Multidimensional Functional Assessment Questionnaire (MFAQ) was developed to provide a profile of the level of functioning and need for services of older persons who live at home but may have some degree of impairment. The MFAQ has been tested on over 6,000 older community residents (Fillenbaum & Smyer, 1981). The IADL subscale consists of seven questions rated on a three-point Likert scale of degree to which the activity can be performed independently. Norms are available for the MFAQ based on 2,146 elderly community residents (George & Fillenbaum, 1985).

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 et al., 1985b; Montgomery, Stull, & Borgatta, 1985a). Objective Burden is defined as the perceived interruption of the tangible aspects of a caregiver's life (B. Ferrell & Mazanec, 2009). Subjective Demand burden is the caregiver's perceived demands of caregiving responsibilities (B. Ferrell & Mazanec, 2009). Subjective Stress Burden is the caregiver's perceived emotional response to the caregiving responsibilities (B. Ferrell & Mazanec, 2009; Montgomery et al., 1985b). The ordinal scale ranges from 1–5 (a lot less to a lot more). Internal consistency for the three dimensions ranges from .82 to .88 (Montgomery et al., 1985a). Cut-off scores were established for each of the burden dimensions, with Objective Burden scores of >23, Subjective Demand score of >15, and Subjective Stress score of >13.5 indicating higher levels of burden (Montgomery et al., 1985a).

Caregiver skills preparedness was assessed using Archbold and colleague's Preparedness for Caregiving Scale. The measure is an eight-item scale of the Family Care Inventory (Archbold, Stewart, Greenlick, & Harvath, 1990). Preparedness is defined as the perceived readiness for multiple domains of the caregiving role, such as providing physical care, providing emotional support, setting up in-home support services, and dealing with the stress of caregiving. Items address caregiver's comfort with various physical and emotional patient needs and are scored from 0 to 4 = very well prepared. The higher the score the more prepared the caregiver feels for caregiving. Internal consistency ranges from 0.88 to 0.93 (Archbold et al., 1990; Schumacher, Stewart, & Archbold, 2007).

Caregiver psychological distress was measured by the Psychological Distress Thermometer. This measure is an efficient, low subject burden method recommended by the National

Comprehensive Cancer Network's Distress Management Guidelines to evaluate psychological distress over the past week, based on a scale of 0 (no distress) to 10 (extremely distressed). A mark of 5 or above indicates a need for intervention (Graves et al., 2007).

Caregiver QOL was assessed using the City of Hope-QOL Scale – Family Version. This tool is a thirty-seven item ordinal instrument that 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 meaning worse QOL. The instrument was revised and tested from 1994–1998 in a study of 219 caregivers of cancer patients. The test-retest reliability was $r=.89$ and internal consistency was $\alpha r=.69$. Factor analysis confirmed the four QOL domains as subscales for the instrument (B. R. Ferrell, Ferrell, Rhiner, & Grant, 1991; B. R. Ferrell, Grant, Borneman, Juarez, & ter Veer, 1999; B. R. Ferrell, Grant, Chan, Ahn, & Ferrell, 1995). Finally, caregiver resource utilization was assessed at all follow-up time points to determine the type of resources caregivers accessed. Specific categories were created by the investigators and included physical support to 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 by caregivers. Data were scanned, audited for accuracy, and read into an SPSS system file. Missing Values Analysis (MVA, SPSS v 19) revealed that values were missing completely at random, thus allowing for imputation using the estimation-maximization method. Descriptive statistics were computed for all variables, and one-way repeated measures Analysis of Variance (ANOVA) was used to test for change over time for all predictor and outcome variables.

Results

Basic demographics data are presented in Table 1. There were no demographic differences found between completers and non-completers. Mean age of the caregivers was 57, with a range of 21–88. The majority of caregivers were non-Hispanic Whites (71%), with 64% being female. Most caregivers were spouses (68%), and 26% were daughters caring for a parent with NSCLC. Overall, 37% of caregivers reported having at least a high school degree, and 61% were college-educated. Caregivers tended to be married or partnered (82%), and lived with their spouse or partner (83%). Most caregivers were employed more than 32 hours per week (34%) or were retired (32%). The majority of caregivers reported having an annual income of greater than \$50,000 (56%), although 20% chose not to provide information on their annual income. Eighty-five percent of caregivers reported having access to a primary care clinician. The majority of caregivers never smoked (53%) or were former smokers (39%). Predominant co-morbidities included cardiovascular, endocrine/metabolic, musculoskeletal, and anxiety/depression. Caregivers were highly functional in instrumental activities of daily living (see Table 2).

Table 3 presents findings for all outcome measures assessed in this study. For caregiver burden, caregivers experienced high levels of Subjective Stress, with mean scores being higher than the cut-off score of 13.5 across all follow-up time points. Subjective Stress was also 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. Caregiver's perceived skills preparedness was high at baseline, but decreased over time, and this difference was statistically significant. Psychological distress was moderate throughout the

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. Out of the four QOL domains, psychological well-being had the worst score, followed by social, spiritual, and physical well-being.

Table 4 presents findings on individual items for caregiver outcome measures. Items with a score of >3.7 (1–5 scale; higher score means higher burden) were selected for the Caregiver Burden Scale. Caregiver's report 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/relatives. For QOL, items with a score of <5 (0–10 scale, lower score means 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.

Finally, findings related to caregiver resource utilization are depicted in Figure 2. The most commonly used source of support was talking to family and friends (96% to 99% over time). This is 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 utilized did not change over time.

Discussion

Findings from this usual care phase of a Program Project in Lung Cancer demonstrated that high caregiver burden and low QOL were common in caregivers caring for a loved one with NSCLC. This finding supports previous studies conducted specifically with caregivers for lung cancer patients, which showed that perceived caregiver burden is high and QOL diminished (Murray et al., 2010; Persson, Ostlund, Wennman-Larsen, Wengstrom, & 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 we did not see significant changes in the scores across time for this 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 cut-offs, the statistically significant increase in the Subjective Demand scores over time suggest that the extent to which the caregiver's perceived care responsibilities 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 has shown that assuming caregiving responsibilities have a negative impact on caregivers' overall QOL (Bergelt, Koch, & Petersen, 2008; Kitrungroter & Cohen, 2006; Mancini et al., 2011). Results from this study support these previous findings. Total QOL scores and the four QOL subscale scores all decreased significantly over time. Our findings also suggest that psychological QOL was the worst across all four domains. Since 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, we observed a significant drop in overall

QOL scores between the 12 and 18 week follow-up, followed by a significant recovery of scores between the 18 and 24 week time points. With this planned analysis we were unable to determine the specific cause of these precipitous changes, but hypothesize that this may be related to fluctuations in patient conditions. Although our findings were specific to caregiver of lung cancer patients, it may also 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., 2012; Given et al., 2011; Kim, Baker, Spillers, & Wellisch, 2006; Kim et al., 2011; Kitrington & Cohen, 2006).

Study limitations included the inclusion of caregivers caring for 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, our findings may not be generalizable across other cancer types and in other settings. Nevertheless, the findings confirm other research in the current cancer caregiver research, and also informed the development of an ongoing caregiver palliative care intervention.

Intervention Development

Based on the findings, an interdisciplinary palliative care intervention for caregivers in NSCLC was developed and is currently being tested. The overall purpose of phase 2 (experimental phase) of this Program Project Grant is to implement and test a palliative care intervention for NSCLC caregivers. Based on findings from this study, the caregiver intervention content included content that addresses caregiver burden, with specific emphasis that focuses on coping with the emotional impact of caregiving. Content on skills preparedness focus 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 addresses their own physical, emotional, social, and spiritual needs.

The intervention began with the collection of baseline information using the same tools that are used in Phase 1. Results of this 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 (social work, nutrition, pulmonary and physical rehabilitation, pain and palliative medicine, chaplain, and psychologist). The ICC's focus is on interdisciplinary support of the patient and caregiver's physical, psychological, social, and spiritual well-being. The interdisciplinary team makes palliative care-related recommendations for both the patient and caregiver, which are all documented in a customized care plan. The care plan for caregivers will be focused on two primary areas – the patient's supportive care needs that the caregiver need help addressing, and caregiver's self-care. Self-care includes healthy living recommendations, exercise, nutrition, managing caregiver's own health, and external support. Referrals to supportive care services are also 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, and spiritual well-being. The sessions are focused on addressing caregiver burden, improving caregiving skills, and development of 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, there is a critical need to develop and implement interventions to support the caregiving role for caregivers of lung cancer

patients. 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. In recent years, palliative care has emerged as a viable model to effectively incorporate the needs of both the patient and family through the utilization 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). National guidelines have been developed by key organizations such as the National Comprehensive Cancer Network (NCCN) and the National Consensus Project for Quality Palliative Care (NCP), and these guidelines recommend incorporating support for family members as an integral part of palliative care (National Comprehensive Cancer Network, 2011; National Consensus Project, 2009). Oncology nurses should be aware of the contents and recommendations of these guidelines that can aid in improving support for caregivers in cancer.

In a recent article, Given and colleagues presented a model of comprehensive caregiver assessment that can aid in identifying their specific areas of needs and assist with selecting the appropriate resources and interventions during the caregiving journey (Given et al., 2012). Areas for assessment include the following: 1) caregiver’s competing demands; 2) living arrangements; 3) caregivers’ employment status; 4) financial needs; 5) demands in the level of care and time needed to provide that care; 6) caregiver’s knowledge and skills related to caregiving; 7) caregiver’s capacity and willingness to care; 8) caregiver’s own physical and mental health needs; 9) available social and family resources; and 10) caregiver’s expectations of the caregiving role (Given et al., 2012). Oncology nurses could utilize these valuable recommendations on conducting a comprehensive caregiver assessment, and re-assess if the patient’s situation and medical condition changes.

In conclusion, the results from 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. These 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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Figure 1.
Family Caregivers' QOL Changes Over Time

Figure 2.
Family Caregiver Resource Use Over Time (%)

Table 1

Caregiver Demographics (n=163)

	Total
	N (%)
<i>Age</i> – mean = 57.23; range: 21–88	
<i>Race</i>	
White	115 (70.6%)
Asian	25 (15.3%)
Black/African American	7 (4.3%)
American Indian/Alaska Native	2 (1.2%)
Native Hawaiian/ Other Pacific Islander	1 (0.6%)
More Than One Race	10 (6.1%)
Unknown/ Unreported	3 (1.8%)
<i>Ethnicity - Hispanic/Latino</i>	
Yes	17 (10.4%)
No	146 (89.6%)
<i>Gender</i>	
Male	58 (35.6%)
Female	105 (64.4%)
<i>Relationship with Patient</i>	
Spouse/Partner	111 (68.1%)
Daughter	26 (16.0%)
Son	7 (4.3%)
Parent	4 (2.5%)
Other	15 (9.2%)
<i>Living Situation</i>	
Spouse/Partner	135 (82.8%)
Children (<18 years old)	21 (12.9%)
Children (>19 years old)	19 (11.7%)
Parent(s)/ Parent(s)-In-Law	12 (7.4%)
Other Relative	10 (6.1%)
Live Alone	6 (3.7%)
Other	2 (1.2%)
<i>Education</i>	
Elementary School	2 (1.2%)
Secondary/High School	61 (37.4%)
College	100 (61.3%)
<i>Marital Status</i>	
Married/Partnered	133 (82.1%)
Single	16 (9.9%)

	Total
	N (%)
Divorced	11 (6.8%)
Separated	1 (0.6%)
Widowed	1 (0.6%)
<i>Employment</i>	
Employed >32 hrs/wk	56 (34.4%)
Retired	52 (31.9%)
Employed <32 hrs/wk	17 (10.4%)
Unemployed	17 (10.4%)
Homemaker	14 (8.6%)
Disabled	5 (3.1%)
Full-time Student	1 (0.6%)
Other	14 (8.6%)
<i>Income</i>	
<\$10000	6 (3.7%)
\$10001 to \$20000	7 (4.3%)
\$20001 to \$30000	6 (3.7%)
\$30001 to \$40000	11 (6.7%)
\$40001 to \$50000	9 (5.5%)
>\$50000	92 (56.4%)
Prefer not to answer	32 (19.6%)
<i>Do you have a primary doctor?</i>	
Yes	138 (84.7%)
No	25 (15.3%)
<i>Smoking History</i>	
Non-Smoker	86 (52.8%)
Former Smoker	63 (38.7%)
Current Smoker	14 (8.6%)
<i>Co-Morbidities (n=102)</i>	
Cardiovascular	62 (60.8%)
Endocrine/Metabolic	36 (35.3%)
Musculoskeletal	34 (33.3%)
Anxiety/Depression	30 (29.4%)
Respiratory	15 (14.8%)
Stomach or Gastrointestinal Disorders	14 (13.7%)
Cancer	9 (8.8%)
Other	21 (20.6%)

Table 2

Family Caregiver Instrumental Activities of Daily Living

Question	Total	
	Mean	SD
Can you use the telephone?	2.00	.000
Get to places out of walking distance?	1.94	.241
Shopping for groceries or clothes?	1.96	.189
Prepare own meals?	1.95	.217
Do your housework?	1.90	.298
Take own medicine?	1.98	.135
Handle own money?	1.98	.135
Overall IADL	13.79	.769

* 1–3 scale; 1= without help, 2=with some help, 3=unable to perform activity

Table 3

Family Caregiver Outcome Measures

	Baseline		7 week		12 week		18 week		24 week		p Value
	Mean	SD	Mean	SD	Mean	SD	Mean	SD	Mean	SD	Main Effect
<i>Caregiver Objective Burden</i> (score of >23 = higher burden)											
Total	15.84	7.63	15.95	7.57	16.30	8.05	14.34	8.22	14.40	8.56	.001
<i>Caregiver Subjective Demand</i> (score of >15 = higher burden)											
Total	10.79	3.55	10.83	3.76	11.41	3.44	11.43	3.17	11.25	3.38	.021
<i>Caregiver Subjective Stress</i> (score of >13.5 = higher burden)											
Total	14.17	3.22	13.87	3.00	13.76	3.12	13.72	2.77	13.73	2.70	.293
<i>Caregiver Skills Preparedness</i> (0–4 scale; higher score = more prepared)											
Total	3.72	.777	3.52	.758	3.56	.768	3.49	.755	3.54	.761	.000
<i>Psychological Distress</i> (0 = no distress; 10 = extremely distressed)											
Total	4.41	2.81	4.57	2.95	4.68	2.94	4.67	2.70	4.84	2.66	.332
<i>Physical Well-Being</i> (0–10 scale; higher score = better QOL)											
Total	7.54	1.98	7.37	1.86	7.26	1.82	6.93	2.01	6.97	2.04	.000
<i>Psychological Well-Being</i> (0–10 scale; higher score = better QOL)											
Total	5.43	1.73	5.32	1.73	5.25	1.71	5.17	1.64	5.12	1.66	.007
<i>Social Well-Being</i> (0–10 scale; higher score = better QOL)											
Total	6.70	1.89	6.16	2.02	6.02	1.95	6.09	1.81	6.02	1.91	.000
<i>Spiritual Well-Being</i> (0–10 scale; higher score = better QOL)											
Total	6.49	2.02	6.75	1.86	6.63	1.87	6.61	1.76	6.37	2.00	.007
<i>Total QOL</i> (0–10 scale; higher score = better QOL)											
Total	6.24	1.52	6.10	1.52	5.99	1.50	5.03	1.46	5.84	1.55	.000

Table 4

Family Caregiver Outcomes - Items Ratings

Question	Baseline			7 weeks			12 weeks			18 weeks			24 weeks		
	N	Mean	SD	N	Mean	SD	N	Mean	SD	N	Mean	SD	N	Mean	SD
<i>Caregiver Burden Scale – Items with score of >3.7</i>															
Time for Self	117	4.15	.925	99	4.13	.888	93	3.98	.944	73	3.89	1.10	69	3.87	1.12
Personal Privacy	70	4.06	1.05	59	4.03	.809	60	3.97	.991	46	3.91	.985	46	3.85	1.01
Time for Recreation	112	4.05	1.09	98	4.22	.856	85	4.01	1.04	76	4.07	.971	71	3.99	1.05
Tension in your life?	163	3.93	.937	144	3.76	.924	131	3.68	.987	120	3.69	.877	122	3.64	.891
Vacation and Trips	106	4.11	1.14	102	4.35	.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	.999	76	4.00	.800	75	3.83	1.08	55	3.82	.945	60	3.97	.882
Time for Friends/Relatives	102	3.87	1.21	78	4.00	.926	79	3.94	1.00	69	3.80	1.08	66	3.85	1.14
<i>QOL – Items with score of <5</i>															
Distress of Patient's Initial Dx	155	1.20	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 Tx	140	3.51	3.39	123	3.50	3.10	117	3.29	2.83	109	3.03	2.61	113	3.01	2.70
Anxiety	133	4.85	3.05	112	5.07	2.95	106	5.06	2.90	101	4.86	2.58	101	4.61	2.73
Fear of 2nd 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	3.40	119	3.52	3.53	105	2.55	3.09	111	2.63	3.00
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	6.60	2.03	120	6.64	1.82	122	6.67	2.06
Uncertainty	133	3.50	3.33	120	3.93	3.30	112	3.91	3.13	106	3.69	2.96	113	3.45	3.10