

## Interdisciplinary Palliative Care Intervention in Metastatic Non—Small-Cell Lung Cancer

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### Abstract

**Palliative care models are lacking in the comprehensive care of patients with lung cancer. We describe the quality of life in patients with non—small-cell lung cancer and the development of an interdisciplinary palliative care intervention. A total of 114 patients reported on function, cognition, social support, symptoms, distress, and quality of life. Results suggest that patients continue to experience high symptom burden and decreased physical well-being.**

**Objective:** Challenges and barriers continue to hinder the integration of palliative care models into comprehensive, ambulatory oncology care. This article aims to describe how symptoms, distress, and quality of life (QOL) data from the usual care phase of a National Cancer Institute—supported Program Project informed the development of an interdisciplinary, tailored palliative care intervention for patients with metastatic non—small-cell lung cancer (NSCLC).

**Methods:** Patients receiving usual care for metastatic NSCLC were recruited into this prospective longitudinal study over a 1-year period. A total of 130 patients with stage IV NSCLC were accrued, and 114 patients had evaluable data. Research nurses assisted patients in completing the clinical section of the data forms, and patients completed surveys and self-reports at baseline and 6, 12, and 24 weeks. **Results:** Patients ranged in age from 40 to 84 years, and 61% were Caucasian non-Hispanic. Sixty-six former (N = 59) and current smokers had an average of 38 pack-year history of smoking. The Karnofsky Performance Status, Instrumental Activities of Daily Living, and Cognitive scores deteriorated significantly ( $P = .001$ ,  $.009$ , and  $.042$ , respectively). Social Activity was stable, whereas Social Support increased significantly. Overall symptom distress score and Total symptom score both significantly increased at 24 weeks ( $P = .003$  and  $.017$ , respectively). Physical Well-Being decreased significantly ( $P = .036$ ), whereas the Functional Assessment of Cancer Therapy-Lung, Functional Assessment of Chronic Illness Therapy-Spirituality Subscale, and Distress scores remained statistically stable over time. **Conclusions:** Patients with metastatic NSCLC continue to experience high symptom burden and diminished physical well-being over time while receiving cancer treatments. An interdisciplinary palliative care intervention is currently being tested to improve symptom burden and overall QOL.

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### Introduction

Since the 2001 Institute of Medicine report on “Improving Palliative Care for Cancer,”<sup>1</sup> important strides have been made in the integration of palliative care as a feasible and effective model of

care for patients with life-threatening illnesses such as cancer. Subsequently, national guidelines have been developed by key organizations, such as the National Comprehensive Cancer Network<sup>2</sup> and the National Consensus Project for Quality Palliative Care.<sup>3</sup>

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The subspecialty of Hospice and Palliative Medicine has been formally recognized by the American Board of Internal Medicine.<sup>4</sup> The American Society of Clinical Oncology also published an update on the current state of the science in palliative cancer care.<sup>5</sup> In this article, 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.”<sup>5</sup> The article further states that the effective provision of palliative cancer care “requires an interdisciplinary team that can provide care in all patient settings, including outpatient clinics.”<sup>5</sup> According to the report, comprehensive cancer care must include palliative care as an integral part of patient and family care.<sup>5</sup> Finally, a recent provisional clinical opinion article published by the American Society of Clinical Oncology recommends that, on the basis of strong evidence, patients with metastatic non–small-cell lung cancer (NSCLC) should be offered concurrent palliative care and standard oncologic care at initial diagnosis.<sup>6</sup>

Despite the ever-expanding evidence that supports the efficacy of palliative care in improving key patient-reported outcomes, such as quality of life (QOL), depression, and overall survival,<sup>4,7</sup> challenges and barriers remain in the integration of models of palliative care into routine oncologic care in ambulatory settings.<sup>4,6,8-10</sup> A survey conducted by Hui and colleagues<sup>9</sup> found that in all National Cancer Institute (NCI)-designated cancer centers, only 60% had a formal outpatient palliative medicine clinic, and this number is even smaller for non–NCI-designated cancer centers (22%). It has been postulated that challenges remain because palliative care as a model of care is inherently diverse, and that one model may not be feasible in other cancer settings or systems.<sup>11</sup> It has also been suggested that the development of disease-specific palliative care models may present patients and families with support mechanisms that are more relevant to their experience and needs.<sup>12</sup> Therefore, it is necessary to develop, test, and disseminate disease-specific models of palliative care that can be successfully integrated into different cancer settings and organizational systems.

The primary purpose of this NCI-funded Program Project Grant is to test the efficacy of an interdisciplinary palliative care intervention mediated by advance practice nurses for patients and families living with metastatic NSCLC. It is well established in the current literature that patients with metastatic NSCLC have tremendous needs in areas such as symptom burden, mood disorders, and overall QOL deficits.<sup>13-25</sup> This article presents findings from the usual care phase of the 5-year project and aims to describe how symptom, distress, and overall QOL data from this phase informed the development of an interdisciplinary, tailored palliative care intervention to meet the physical, psychologic, social, and spiritual needs of patients with NSCLC with metastatic disease.

## Patients and Methods

### Design

**Patient Selection.** Study participants were recruited from the Medical Oncology Adult Ambulatory Care Clinic at an NCI-designated comprehensive cancer center. Eligibility criteria included a diagnosis of stage IV metastatic NSCLC, aged 18 years or more, at least 1 month from diagnosis, and having no other cancer diagnosis within the last 5 years. Eligible patients were recruited to assess Usual Care in Phase 1 of this 2-phase Program

Project Grant. Of the 130 patients with late-stage disease who were accrued for phase I of this study, 114 were eligible for analysis (consented with baseline data). Of the 130 patients with late-stage disease who consented to participate in the study, 16 did not provide baseline data and therefore were ineligible for analysis. Of the 114 remaining phase I patients, 15 died or dropped out of the study because of severe illness before 24 weeks. Their data are included in the results where possible.

### Procedure

The institutional review board approved the study protocol and monitored study progress. Research nurses approached all individuals meeting eligibility criteria during a regularly scheduled clinic visit. Written informed consent was obtained from all patients before participation in this study. On informed consent, patients completed baseline assessment that included basic demographics and outcome measures to assess physical function/cognitive status, social activities and support, symptom characteristics, psychologic distress, spiritual well-being, and overall QOL. Specific physical function/cognitive status measures, such as the timed “up and go” test, were completed by the Research Nurse. All outcome measures were repeated later at 6, 12, and 24 weeks after accrual. A chart audit was conducted at the 24-week evaluation to collect disease and treatment variables.

### Instruments

Key demographic, disease, and treatment variables were captured through the Chart Audit Data Form. The form was designed to describe the study population and for analysis of influencing variables at baseline and at 6 months post-accrual. Data collected include age, gender, stage of disease, comorbidities, number of chemotherapy cycles completed, number and total radiation treatments, number and length of hospitalizations, number and length of intensive care unit admissions, number of clinic visits, number of urgent care visits, and readmissions while enrolled in the study.

Physical function and cognitive status were assessed using the following: (1) The Instrumental Activities of Daily Living Scale consists of 7 questions rated on a 3-point Likert scale that measures level of the activity that can be performed independently by patients. Norms are available based on 2146 elderly community residents.<sup>26,27</sup> (2) The Activities of Daily Living Scale contains measures of higher levels of physical functioning and includes items on vigorous activities (running, lifting heavy items) and basic activities (bathing and dressing). The 10 items are rated on a 3-point Likert scale of independent performance of the activity.<sup>28</sup> (3) The Blessed Orientation-Memory-Concentration Test consists of 6 questions designed to screen for gross cognitive impairment.<sup>29,30</sup> A score > 11 signifies cognitive impairment. The test has excellent validity as a screening instrument, correlates highly with clinicians' ratings of dementia severity ( $r = 0.89$ ), and discriminates between patients with mild, moderate, and severe cognitive deficits. (4) The Timed “Up and Go” is a test of physical mobility. The test, measured in seconds, is the time it takes for an individual to stand up from a standard arm-chair (approximate seat height of 46 cm), walk a distance of 3 m (10 feet), turn, walk back to the chair, and sit down again. Intra-rater and inter-rater reliability were extremely high (intra-class correlation 0.99).<sup>31</sup> (5) Percent unintentional

Table 1 Demographic Characteristics (N = 114)		
	Frequency	Valid Percent
<b>Religious Preference</b>		
Protestant	48	42.0
Catholic	33	28.8
No religion	18	15.7
Other	15	13.5
<b>Gender</b>		
Male	41	36.0
Female	73	64.0
<b>Education Completed</b>		
Elementary	2	1.8
Secondary/high school	36	31.9
College	75	66.4
<b>Marital Status</b>		
Married	82	71.9
Other	32	28.1
<b>Employment Status (N = 114/114; 100%)<sup>a</sup></b>		
Employed > 32 h/wk	22	19.3
Employed < 32 h/wk	9	7.9
Homemaker	8	7.0
On medical leave	13	11.4
Disabled	17	14.9
Unemployed	9	7.9
Retired	43	37.7
Other	4	3.5
<b>Income</b>		
≤ \$10,000	6	5.3
\$10,001-\$20,000	6	5.3
\$20,001-\$30,000	9	7.9
\$30,001-\$40,000	7	6.1
\$40,001-\$50,000	8	7.0
> \$50,000	47	41.2
Prefer not to answer	31	27.2
<b>Patient Has Caregiver</b>		
Yes	99	86.8
No	12	10.5
<b>Ethnicity: Hispanic/Latino?</b>		
Yes	11	9.6
No	103	90.4
<b>Race</b>		
American Indian/Alaska Native	1	.9
Asian	23	20.2
Black/African American	5	4.4
Native Hawaiian or Other Pacific Islander	3	2.6
White (includes Latino)	80	70.2
> 1 race	2	1.8
<b>Live Alone?</b>		
Yes	12	7.8%
No	102	92.2

Table 1 Continued		
	Frequency	Valid Percent
<b>Smoking History</b>		
Current smoker	9	7.9
Former smoker	59	51.7
Nonsmoker	46	40.4
No. of pack-y history for smoking (N = 66)	Mean = 37.67; SD = 28.99	
Years since quitting smoking (N = 59)	Mean = 13.69; SD = 14.57	

<sup>a</sup>Respondents may check all that apply; total may exceed 100%.

weight loss and body mass index (BMI) were used to determine nutritional status. Patients were asked to quantify the amount of unintentional weight loss for the past 6 months, and weight and height were measured to calculate BMI.

Social activities and support were assessed using the following: (1) The Medical Outcomes Study Social Activity Limitations Scale is a 4-item scale that assesses the extent to which physical or emotional problems have interfered with social activities. All items are rated on a 5-point Likert scale, with response categories varying with each item. The mean of the total score is transformed to a scale of 0 to 100, with a higher number indicating greater support. The scale correlates significantly with a range of measures: role limitations due to physical ( $r = 0.52$ ) and emotional ( $r = 0.49$ ) health, psychologic distress ( $r = 0.64$ ), and pain ( $r = 0.55$ ).<sup>28</sup> (2) The Medical Outcomes Study Social Support Survey: Emotional/Information and Tangible Subscales were used to determine access to material aid/behavioral assistance and advice, information, guidance, or feedback from others. All but 1 item is rated on a 5-point Likert scale. Internal consistency of the subscales and total score are excellent (alpha coefficient > 0.91). Convergent validity was demonstrated by significant correlations of social support total score with measures of mental health ( $r = 0.45$ ).<sup>28</sup>

Symptom characteristics were assessed using the Memorial Symptom Assessment Scale (MSAS). The MSAS is a 32-item tool used to measure the prevalence, characteristics, and distress of common symptoms. The scoring of the MSAS yields several subscale scores and an overall symptom distress score (Global Distress Index). Symptom severity for each of the 32 symptoms is obtained for experience occurring within the past week (7 days), with scoring divided into 4 categories: slight, moderate, severe, and very severe. The Physical Symptom Subscale of the MSAS is the average of the frequency, severity, and distress associated with 12 prevalent physical symptoms. The Psychological Symptom Subscale of the MSAS is the average of the frequency, severity, and distress associated with 6 prevalent psychologic symptoms. The Total MSAS score is the average of the symptom scores of all 32 items in the instrument. Finally, overall symptom distress is the mean of the frequency of 4 prevalent psychologic symptoms (feeling sad, worrying, feeling irritable, feeling nervous) and the distress associated with 6 prevalent physical symptoms (lack of appetite, pain, lack of energy, feeling drowsy, constipation, dry mouth). Validity testing has included correlation of the MSAS with the RAND Mental Health Inventory well-being subscale, RAND distress subscale, Symptom Distress

**Table 2** Symptoms Experienced by Patients Over Time

Symptoms	No. of Patients With Symptoms (N)				Severity x (SD)				Distress x (SD)			
	Baseline (N = 114)	6 Wks (N = 102)	12 Wks (N = 93)	24 Wks (N = 81)	Baseline	6 Wks	12 Wks	24 Wks	Baseline	6 Wks	12 Wks	24 Wks
Difficulty concentrating	52	50	47	46	1.33 (0.51)	1.34 (0.56)	1.32 (0.52)	1.46 (0.59)	2.10 (1.1)	2.08 (1.0)	2.15 (0.86)	2.28 (1.03)
<sup>a</sup> Pain	84	72	63	56	1.62 (0.76)	1.78 (0.74)	1.63 (0.68)	1.68 (0.66)	2.54 (1.2)	2.56 (0.99)	2.35 (0.75)	2.61 (1.02)
<sup>a</sup> Lack of energy	98	88	75	73	1.90 (0.86)	1.85 (0.77)	1.84 (0.74)	1.92 (0.83)	2.73 (1.2)	2.60 (1.2)	2.48 (1.2)	2.71 (1.25)
Cough	85	75	63	52	1.47 (0.73)	1.45 (0.66)	1.59 (0.80)	1.67 (0.76)	2.24 (1.2)	2.15 (1.1)	2.11 (1.0)	2.31 (0.98)
Feeling nervous	76	58	53	50	1.43 (0.64)	1.53 (0.63)	1.40 (0.53)	1.50 (0.65)	2.29 (1.1)	2.33 (0.91)	2.11 (0.80)	2.30 (1.04)
Dry mouth	60	66	55	55	1.52 (0.60)	1.50 (0.69)	1.56 (0.74)	1.64 (0.70)	1.93 (1.0)	1.97 (1.0)	1.98 (0.81)	2.15 (0.99)
Nausea	45	46	39	39	1.33 (0.52)	1.52 (0.72)	1.33 (0.53)	1.54 (0.64)	2.18 (0.86)	2.17 (1.0)	2.15 (0.81)	2.18 (0.91)
Feeling drowsy	67	67	56	55	1.55 (0.63)	1.57 (0.70)	1.50 (0.60)	1.73 (0.68)	1.96 (1.1)	1.91 (1.0)	1.88 (0.88)	2.18 (1.05)
<sup>a</sup> Numbness/tingling in hands/feet	58	57	45	45	1.71 (0.80)	1.70 (0.82)	1.82 (0.72)	1.80 (0.63)	2.51 (1.2)	2.40 (1.2)	2.49 (0.94)	2.47 (0.97)
<sup>a</sup> Difficulty sleeping	87	71	60	50	1.83 (0.82)	1.83 (0.76)	1.78 (0.83)	1.82 (0.83)	2.39 (1.1)	2.46 (1.0)	2.47 (1.2)	2.59 (1.21)
Feeling bloated	42	33	31	25	1.69 (0.81)	1.76 (0.79)	1.52 (0.72)	1.56 (0.77)	2.38 (1.0)	2.27 (0.98)	2.26 (1.0)	2.42 (1.02)
Problems with urination	26	22	16	13	1.38 (0.57)	1.41 (0.59)	1.38 (0.50)	1.85 (0.90)	2.08 (1.0)	2.04 (0.83)	2.06 (0.93)	2.69 (1.03)
Vomiting	17	15	14	14	1.29 (0.47)	1.40 (0.51)	1.36 (0.63)	1.43 (0.51)	2.06 (1.1)	2.07 (0.88)	2.43 (0.94)	2.08 (0.64)
<sup>a</sup> Shortness of breath	78	60	53	50	1.94 (0.81)	1.85 (0.76)	1.87 (0.81)	1.74 (0.69)	2.75 (1.3)	2.50 (1.2)	2.60 (1.1)	2.66 (1.02)
Diarrhea	42	35	29	28	1.62 (0.73)	1.46 (0.66)	1.52 (0.51)	1.54 (0.51)	2.14 (1.2)	1.94 (1.1)	2.10 (0.67)	2.11 (0.75)
Feeling sad	59	55	47	48	1.59 (0.70)	1.67 (0.70)	1.55 (0.54)	1.58 (0.71)	2.47 (1.1)	2.24 (0.95)	2.36 (0.79)	2.52 (0.92)
Sweats	35	29	25	16	1.57 (0.78)	1.62 (0.82)	1.60 (0.58)	1.69 (0.60)	2.12 (1.2)	2.07 (0.96)	2.00 (0.82)	2.24 (0.66)
Worrying	80	66	56	50	1.74 (0.82)	1.67 (0.69)	1.55 (0.57)	1.80 (0.88)	2.58 (1.1)	2.42 (0.84)	2.29 (0.91)	2.62 (1.14)
<sup>a</sup> Problems with sexual interest or activity	43	41	32	26	2.02 (1.0)	2.10 (1.0)	2.00 (1.0)	1.92 (1.0)	2.55 (1.4)	2.41 (1.1)	2.22 (1.2)	2.58 (1.14)
Itching	52	47	38	34	1.65 (0.81)	1.60 (0.77)	1.87 (1.0)	1.71 (0.87)	2.10 (1.2)	2.26 (1.0)	2.66 (1.3)	2.15 (1.02)
<sup>a</sup> Lack of appetite	66	55	42	44	1.65 (0.69)	1.76 (0.72)	1.76 (0.73)	1.91 (0.80)	2.26 (1.2)	2.33 (1.0)	2.21 (1.2)	2.45 (1.13)
Dizziness	46	47	33	32	1.52 (0.72)	1.40 (0.58)	1.42 (0.50)	1.56 (0.62)	2.33 (1.2)	2.13 (0.86)	2.18 (0.64)	2.41 (0.80)
Difficulty swallowing	16	16	13	11	1.19 (0.40)	1.38 (0.62)	1.31 (0.48)	1.73 (0.79)	2.00 (1.1)	2.19 (0.66)	2.08 (0.64)	2.36 (1.03)
Feeling irritable	64	55	42	37	1.56 (0.77)	1.56 (0.66)	1.50 (0.60)	1.62 (0.68)	2.20 (1.1)	2.19 (0.98)	2.19 (0.86)	2.32 (0.94)
Rash on my face	28	29	25	26	1.79 (0.92)	1.41 (0.63)	1.84 (0.80)	1.62 (0.75)	2.32 (1.3)	2.10 (1.0)	2.44 (1.0)	2.42 (0.90)
Rash on my body	33	31	28	26	1.39 (0.61)	1.61 (0.84)	1.82 (0.98)	1.81 (0.80)	2.06 (1.2)	2.16 (1.2)	2.54 (1.2)	2.37 (1.01)
Crusting of my skin	25	31	22	18	1.52 (0.77)	1.58 (0.72)	1.86 (0.99)	2.00 (0.77)	2.40 (1.3)	2.30 (1.1)	2.50 (1.0)	2.78 (0.94)
<sup>a</sup> Dry skin	72	67	57	44	1.79 (0.80)	1.97 (0.83)	1.81 (0.90)	2.02 (0.79)	2.35 (1.2)	2.39 (1.2)	2.19 (1.0)	2.38 (1.13)
<sup>a</sup> Nail changes (swelling of nail folds or brittle nails)	35	35	34	29	1.82 (0.90)	1.63 (0.60)	1.76 (0.83)	1.83 (0.89)	1.94 (0.96)	2.14 (0.81)	2.24 (0.92)	2.17 (1.10)
Mouth sores	16	26	19	17	0.19 (0.51)	0.29 (0.52)	0.26 (0.55)	0.28 (0.64)	2.31 (0.48)	2.08 (0.74)	2.21 (0.71)	2.65 (1.06)

Table 2 Continued

Symptoms	No. of Patients With Symptoms (N)				Severity x (SD)				Distress x (SD)			
	Baseline (N = 114)	6 Wks (N = 102)	12 Wks (N = 93)	24 Wks (N = 81)	Baseline	6 Wks	12 Wks	24 Wks	Baseline	6 Wks	12 Wks	24 Wks
Change in the way food tastes	48	44	41	37	0.76 (1.1)	0.80 (1.1)	0.76 (1.0)	0.90 (1.1)	2.60 (1.3)	2.86 (1.0)	2.49 (1.0)	2.65 (0.98)
Weight loss	48	43	39	30	0.67 (0.90)	0.57 (0.77)	.62 (0.81)	0.65 (0.96)	2.21 (1.2)	2.16 (1.1)	2.21 (1.0)	2.50 (1.08)
Hair loss	37	42	37	27	0.61 (1.1)	0.88 (1.3)	0.93 (1.4)	0.65 (1.1)	2.70 (1.3)	2.60 (1.2)	2.78 (1.4)	2.85 (1.06)
Constipation	56	49	37	35	0.90 (1.1)	0.85 (1.1)	0.74 (1.1)	0.87 (1.1)	2.87 (1.2)	2.51 (1.1)	2.73 (1.2)	2.86 (1.03)
Swelling of arms or legs	27	25	23	21	0.38 (0.80)	0.37 (0.73)	0.36 (0.69)	0.51 (0.93)	2.59 (1.2)	2.32 (0.90)	2.22 (0.95)	2.86 (1.11)
"I don't look like myself"	35	40	34	33	0.57 (1.0)	0.70 (1.1)	0.66 (1.0)	0.71 (1.0)	2.74 (1.1)	2.58 (1.1)	2.53 (1.1)	2.64 (0.93)
Changes in skin	41	36	32	37	0.61 (0.94)	0.68 (1.1)	0.69 (1.1)	0.68 (0.97)	2.49 (1.0)	2.94 (1.2)	2.81 (0.90)	2.47 (0.72)
Sensitivity to touch at the surgical site	9	14	20	11	0.32 (0.94)	0.17 (0.41)	0.33 (0.70)	0.24 (0.68)	2.33 (1.2)	1.86 (0.53)	2.20 (1.0)	2.45 (0.93)
*Electric shocks/burning pain at site	4	4	7	7	0.22 (0.86)	0.05 (0.21)	0.09 (0.32)	0.10 (0.34)	3.25 (1.3)	2.00 (0.00)	2.43 (0.79)	2.29 (0.49)
Shoulder pain since surgery	6	8	12	10	0.31 (1.0)	0.11 (0.39)	0.22 (0.61)	0.22 (0.61)	3.17 (0.98)	2.38 (0.74)	2.67 (0.89)	3.20 (1.03)

\*Symptoms with higher severity.

Scale, Functional Living Index-Cancer, Karnofsky Performance Scale, and Memorial Pain Assessment Card. Reliability and validity have been reported in studies on patients with cancer.<sup>32</sup>

QOL was assessed using the following: The Psychological Distress Thermometer is an efficient, low subject burden method to evaluate patient distress over the past week, based on a scale of 1 to 10. A mark of  $\geq 5$  indicates a need for intervention.<sup>33</sup> The Functional Assessment of Cancer Therapy-Lung (version 4) Tool is a 37-item self-reported instrument that measures multidimensional QOL.<sup>34</sup> This tool is composed of 5 subscales: physical, social/family, emotional, functional well-being, and the lung cancer symptom index. Each item is rated on a 5-point Likert scale.<sup>35-37</sup> The Functional Assessment of Chronic Illness Therapy-Spirituality Subscale is a 12-item tool that assesses the spiritual well-being of patients with cancer using a 5-point Likert scale. Psychometric properties of the Functional Assessment of Chronic Illness Therapy-Spirituality Subscale were tested in a sample containing 1617 subjects of whom the majority had a diagnosis of early stage and metastatic cancer (83.1%).<sup>38</sup>

**Data Analysis**

Scannable data forms developed using the Remark system were completed by research nurses and the patients. Data were scanned, audited for accuracy, and analyzed using SPSS v. 19.0. Missing Values Analysis (SPSS Inc., Chicago, IL) comparing the 99 patients who completed the 4 sets of measures (baseline through 24 weeks) who did not drop out because of mortality or severe illness. Values were found to be missing completely at random, thus allowing for imputation using the estimation-maximization method. Descriptive statistics were computed for all variables, all scales were scored according to instrument guidelines, and 1-way repeated-measures analysis of variance was used to test for change over time for all predictor and outcome variables.

**Results**

**Demographics**

Table 1 provides detailed demographics data for patients enrolled in the study. Age ranged from 40 to 84 years (mean, 61.6; SD, 9.61), and 36% of the sample were male. Patients were predominantly Protestant; 10% were Hispanic/Latino, 20% were Asian, 4% were African American, 5% were "other," and 61% were Caucasian/non-Hispanic. Approximately 2 of 3 of patients were college educated, and 87% had caregivers (only 8% lived alone). Patients were most likely retired (34%) or employed only part-time (18%). The majority of the patients' incomes were greater than \$50,000 (41%) or they preferred not to answer (27%). More than half were former smokers, 9 patients continued to smoke, and 40% were never-smokers. Sixty-six patients had an average 38 pack-year history of smoking. Fifty-nine patients had quit smoking, ranging from 1 year after diagnosis to 47 years before diagnosis.

**Physical Function/Cognitive Status and Social Activities/Social Support**

Functional status (Karnofsky Performance Status) and cognitive status were largely intact. One third of the patients demonstrated poor mobility, and 51% had at least 1 deficit in Instrumental Activities of Daily Living. The average Activities of Daily Living

**Table 3** Symptom Assessment Subscale Scores Over Time

Scale/Measure <sup>a</sup>	Baseline	6 Wks	12 Wks	24 Wks	P Value
	X (SD)	X (SD)	X (SD)	X (SD)	
<b>MSAS</b>					
• Overall Symptom Distress	1.21 (0.75)	1.19 (0.78)	1.03 (0.71)	1.28 (0.84)	.003
• Physical Symptoms	1.00 (0.68)	1.07 (0.91)	0.95 (0.66)	1.10 (0.79)	.260
• Psychologic Symptoms	1.10 (0.84)	1.07 (0.75)	0.98 (0.75)	1.14 (0.88)	.110
• Total Symptom Score <sup>b</sup>	1.04 (0.60)	1.01 (0.60)	0.98 (0.54)	1.14 (0.61)	.017

Abbreviation: MSAS = Memorial Symptom Assessment Scale.

<sup>a</sup>Higher scores represent more symptomatology.

<sup>b</sup>Six- and 12-week scores are significantly lower than 24-week scores.

Scale score was near normal (98.03) with a range of 58 to 100 (100 = completely intact). Less than half of the patients (46%) exercised routinely, but of those who did, the average approached 4 days per week. Karnofsky Performance Status and Instrumental Activities of Daily Living were significantly worse at 24 weeks than at baseline. Cognitive score was significantly lower at baseline and 24 weeks than at the other 2 time periods. All patients were able to complete the Timed Up and Go assessment in approximately 10 to 11 seconds, and there were no significant differences over time. Approximately one third of the patients had lost weight before accrual, and food intake had decreased (37%) or remained unchanged (52%). Few patients were underweight, as judged by their BMI. There were few abnormal laboratory values for these patients at baseline, although 39% had low hemoglobin, 18% had a high white blood cell count, 20% had a high blood urea nitrogen, and 10% had high creatinine. Social activity was preserved, but Social Support total score and subscale scores all improved significantly at 12 and 24 weeks.

**Symptoms**

Individual symptoms across 4 time periods (baseline, 6, 12, and 24 weeks) are shown in Table 2. Severity is rated on a scale of 1 (slight) to 4 (very severe); distress is rated on a scale of 1 (not at all)

to 5 (very much). Patients reported higher severity scores with symptoms such as problems with sexual interest or activity, difficulty sleeping, lack of energy, shortness of breath, dry skin, nail changes, numbness/tingling in the hands/feet, lack of appetite, and pain in all 4 time periods. There were significant changes in the overall symptom distress score, and the total symptom score over time in that the 12-week distress level was significantly better than all other time periods ( $P = .003$ ), and the 24-week score was significantly worse than the 6- and 12-week total symptom scores (Table 3).

**QOL**

Scores from the Functional Assessment of Cancer Therapy-Lung and Functional Assessment of Chronic Illness Therapy-Spirituality Subscale, as well as the distress thermometer, are shown in Table 4, along with the significance of their changes over time. Only physical well-being demonstrated a significant decrease in QOL between baseline vs. 6 weeks and 24 weeks ( $P = .036$ ). Distress did not change appreciably.

**Chart Audit**

Chart audit findings are shown in Table 5. Approximately one quarter of the patients were newly diagnosed (up to 3 months),

**Table 4** QOL and Psychologic Distress Over Time

Scale/Measure <sup>a</sup>	Baseline	6 Wks	12 Wks	24 Wks	P Value
	X (SD)	X (SD)	X (SD)	X (SD)	
<b>QOL</b>					
• Physical Well-Being <sup>b</sup>	22.08 (6.04)	20.41 (7.10)	21.05 (7.02)	21.84 (6.08)	.036
• Social/Family Well-Being	21.93 (4.63)	22.28 (4.62)	22.54 (4.30)	21.84 (4.86)	.387
• Emotional Well-Being	18.44 (4.81)	18.75 (4.39)	19.08 (4.39)	18.84 (4.73)	.525
• Functional Well-Being	17.04 (5.18)	16.98 (5.12)	17.49 (5.12)	16.51 (5.38)	.491
• Lung Cancer Scale	24.50 (4.75)	24.35 (5.70)	24.73 (5.58)	24.52 (5.76)	.851
• General Well-Being	78.91 (16.39)	78.52 (15.66)	79.36 (16.83)	79.28 (16.36)	.899
• Overall Well-Being Lung Cancer	102.02 (19.51)	102.70 (19.91)	103.35 (21.34)	103.55 (20.56)	.868
<b>Spirituality</b>					
• Meaning	25.89 (5.86)	25.64 (6.17)	25.80 (6.07)	24.86 (7.05)	.116
• Faith	11.62 (4.57)	12.00 (4.43)	11.92 (4.19)	11.41 (4.62)	.122
• Total	37.50 (8.86)	37.64 (9.15)	37.72 (9.15)	36.27 (10.30)	.054
<b>Distress</b>	2.73 (2.56)	3.16 (2.78)	2.96 (2.61)	2.77 (2.52)	.490

Abbreviation: QOL = quality of life.

<sup>a</sup>Higher scores represent higher QOL, except for Distress, for which with a score of 0-10, 10 represents high distress.

<sup>b</sup>Baseline is significantly different than 6 and 24 weeks.

**Table 5** Chart Audit Findings

	Frequency	Valid Percent
<b>Referrals to Support Services (N = 29/114; 25.4%)</b>		
Chaplain	1	3.4
Nutrition	6	20.7
Pain/palliative medicine	3	10.3
Psychology/psychiatry	5	17.2
PT/OT	3	10.3
Pulmonary rehabilitation	5	17.2
Social work	15	51.7
<b>Comorbidities (N = 95/114; 83%)</b>		
Neoplasm	3	3.2
Endocrine/metabolic/immunity	26	27.4
Obesity	4	4.2
Blood and blood-forming organ	2	2.1
Psychiatric disorders (anxiety, depression)	24	25.3
Nervous system/stroke	3	3.2
Sense organs	1	1.1
Circulatory system/cardiac	61	64.2
Respiratory system	22	23.2
Digestive system	19	20.0
Genitourinary system	9	9.5
Skin/subcutaneous tissue	3	3.2
Musculoskeletal system/connective tissue	22	23.2
<b>Months Since Diagnosis</b>		
Up to 3	31	27.2
3-6	14	12.3
6-12	19	16.7
> 12	50	43.9
<b>Treatment</b>		
Surgery <sup>a</sup>	11	9.6
Chemotherapy only	98	86.0
Chemotherapy and radiation	5	4.4
No chemotherapy or radiation	11	9.6
<b>Advance Care Planning</b>		
Advance Directives	7	6.1
Code status		
Full	103	90.4
DNR	6	5.3
<b>Expired N = 18/114 (15.7%)</b>		
<b>Chemotherapy in Last 2 Wks of Life (N = 3/18)</b>	3	16.7
<b>Hospice Referral</b>	11	61.1
<b>Place of Death</b>		
Home	8	7.0
Hospital	3	2.6
Unknown	7	6.1

**Table 5** Continued

	Frequency	Valid Percent
<b>Admissions/Readmissions (N = 23/114; 20.2%)</b>		
Type of admission		
Scheduled	12	52.2
Unscheduled	11	47.8
Disposition		
Home — independent care	21	91.3
In-hospital death	2	8.7

Abbreviations: DNR = do not resuscitate; OT = occupational therapy; PT = physical therapy. <sup>a</sup>One patient in the study underwent a second surgery.

whereas 44% had been diagnosed more than 12 months ago. The majority of patients (84%) had ≥ 1 comorbidities, averaging approximately 4 per individual, primarily cardiovascular disease (including hypertension and hyperlipidemia). At baseline, patients reported taking an average of 7 medications. Most patients had chemotherapy (86%), with only 4.4% treated with concurrent or sequential chemoradiation. Surgery (9.6%) and hospitalization (20%) were sparse among these patients with late-stage disease. Reasons for hospital admissions over the 6-month period were primarily related to symptom management (58.8%). More than 90% of patients were discharged home without home care services. Of the patients who had advance directives, the majority were on full code status (90.4%). Only 29 patients (26%) had referrals to support services, and referrals were made primarily to social work (51.7%), nutrition (20.7%), pulmonary rehabilitation (17.2%), and pain and palliative medicine (10.3%). Approximately 61.1% of patients were referred to hospice. Most of the 43 (37.6%) unscheduled encounters were calls to urgent care or clinics. The primary reason for an encounter was for symptom management (95%), including pain (41.5%), dyspnea/cough/hemoptysis (26.8%), fever (22%), nausea/vomiting (9.8), and constipation/diarrhea (19.5%). Eight patients (7%) were found to have died at home, and 3 patients (2.6%) died in the hospital.

## Discussion

Findings from this usual care phase of a Program Project in Lung Cancer demonstrated many concerns regarding functional status, symptoms, and physical well-being. Numerous studies have reported that symptom burden and symptom distress are high for patients with metastatic NSCLC, and our findings confirm these previous reports.<sup>19,21,25,39,40</sup> Studies also suggest that symptom burden and QOL have independent prognostic values for overall survival in advanced NSCLC.<sup>22,41</sup> In this study, symptoms with the highest reported severity included sexuality issues, sleep disturbance, fatigue, dyspnea, dry skin, paronychia, neuropathy, lack of appetite, and pain. These symptoms have been reported in previous studies as common and severe for patients with NSCLC and may be related to both treatment toxicities and advanced disease.<sup>20,39,42-44</sup>

Overall, our findings revealed deteriorations of functional status and physical well-being coupled with worsening of symptom distress over time in this cohort of patients with metastatic

NSCLC. In advanced disease and terminal illness, increased symptom burden and deteriorations in overall QOL have been described in the current literature.<sup>45</sup> This phenomenon points to the need for improved, comprehensive models of palliative care for patients with NSCLC with advanced, incurable disease that focus on minimizing the negative effects of the expected symptom burden related to terminal illness while maximizing overall QOL.

### Intervention Development

Findings from the usual care phase of this Program Project Grant informed the development of the interdisciplinary palliative care intervention for patients with NSCLC. The overall purpose of phase 2 (experimental phase) of this Program Project Grant is to implement and test a palliative care intervention for patients with stage IV, metastatic NSCLC. The core element of the palliative care intervention consists of an Interdisciplinary Care Conference (ICC) that is conducted for each patient, with attendance by 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 focused on interdisciplinary and aggressive symptom management, as well as supporting the patient's psychologic, social, and spiritual well-being. Table 6 presents detailed procedures for the ICC. Before each ICC, a Research Nurse gathers all baseline assessment data completed by the patient, reviews the responses, and transcribes assessment results onto an Interdisciplinary Care Plan specifically designed for this project. The care plan includes a comprehensive section on patients' current symptoms and symptom intensity. Data also include basic sociodemographic, disease, and treatment information. Information from the care plan is then presented to the team during the ICC by the Research Nurse. After case presentation, the interdisciplinary team makes palliative care-related recommendations, including comprehensive symptom management, which are all documented on the care plan. On the basis of recommendations, referrals to supportive care services are initiated. The Research Nurse conducts follow-up evaluations with each patient and communicates with the patient's treating oncologist to review the patient's status and determine whether further recommendations are needed. This phase of the study will continue for 2 years.

In addition to the interdisciplinary care, all patients receive educational materials and participate in 4 educational sessions that are administered in face-to-face or telephone format by the nurse, depending on patient preference. The session contents are divided into 4 QOL domains: physical, psychologic, social, and spiritual well-being (Table 6). The physical well-being content of the education sessions is focused primarily on disease- and treatment-related symptoms, and findings from this study informed the development of the physical well-being content. Supplemental materials are available that address end-of-life care issues for patients who are imminently dying. During each session, the patient identifies topics of interest, and these topics are then discussed during the sessions, allowing for tailoring of content that is pertinent to each patient's needs. The Research Nurse provides recommended resources to help patients manage palliative care-related issues and initiates any further referrals to palliative care services if needed.

**Table 6** Interdisciplinary Care Conference Procedures and Education Session Content

Interdisciplinary Care Conference	
1.	Research Nurse reviews patient baseline assessment data.
2.	Research Nurse transcribes assessment results into Interdisciplinary Care Plan.
3.	Care Plan data presented at the ICC for each patient, including: <ol style="list-style-type: none"> <li>Sociodemographic data (age, ethnicity, gender, marital status, employment, religion, caregiving status, insurance)</li> <li>Disease and Treatment (date of first treatment, type of treatment, other cancer diagnosis, BMI, height, WBC, Hgb, albumin, BUN, creatinine), medications</li> <li>Health Status (smoking, comorbidities, KPS, advance directive, ADLs, IADLs, food intake, exercise behavior)</li> <li>Physical and psychologic symptoms (MSAS), pain rating</li> <li>Psychologic distress (Distress Thermometer)</li> <li>Social support and activities</li> <li>Spiritual concerns</li> </ol>
4.	On the basis of case presentation, interdisciplinary team professionals make supportive care-related recommendations
5.	Recommendations initiated by Research Nurse and documented on the Interdisciplinary Care Plan. Each interdisciplinary team member and patient receives a copy of the Care Plan.
6.	Care Plan revised and updated as needed.
Patient Educational Session Content	
Session 1: Physical Well-Being	<ul style="list-style-type: none"> <li>Breathing problems/cough</li> <li>Pain</li> <li>Constipation</li> <li>Fatigue</li> <li>Sleep problems</li> <li>Nausea and vomiting</li> <li>Appetite problems/weight loss</li> <li>Skin, hair, and nail changes</li> <li>Smoking cessation</li> </ul>
Session 2: Psychologic Well-Being	<ul style="list-style-type: none"> <li>Worry and fear</li> <li>Depression</li> <li>Anger</li> <li>Cognitive changes</li> </ul>
Session 3: Social Well-Being	<ul style="list-style-type: none"> <li>Changes with relationships</li> <li>Communication</li> <li>Sexual changes</li> <li>Social support</li> <li>Financial burdens</li> <li>Healthcare planning</li> </ul>
Session 4: Spiritual Well-Being	<ul style="list-style-type: none"> <li>Purpose and meaning in life</li> <li>Hope</li> <li>Redefining self and priorities in life</li> <li>Inner strength</li> <li>Uncertainty</li> <li>Positive changes</li> </ul>

Abbreviations: ADL = activities of daily living; BMI = body mass index; BUN = blood urea nitrogen; Hgb = hemoglobin; IADL = Instrumental Activities of Daily Living; ICC = Interdisciplinary Care Conference; KPS = Karnofsky Performance Status; MSAS = Memorial Symptom Assessment Scale; WBC = white blood cell.

### Conclusion

The results from this study suggest that patients with metastatic NSCLC experience functional deficits, deteriorations in physical well-being, and worsening of overall symptom distress over time. Although results from the study largely confirmed findings from

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previous studies in NSCLC, the design allowed for a comprehensive assessment of palliative care and QOL needs over time, and included descriptions of physical function, cognitive status, and hospital resource use. Comprehensive QOL assessment and interdisciplinary collaborations that focus on supporting physical well-being and aggressive symptoms management may be key to improving the quality of comprehensive cancer care for this vulnerable population with cancer.

## Clinical Practice Points

- Palliative cancer care is defined as the integration into cancer care of therapies that address multiple issues that cause distress for patients and their families and affect their life quality. Comprehensive cancer care must include palliative care as an integral part of patient and family care.
- To date, challenges and barriers remain in the integration of models of palliative care into routine oncologic care in ambulatory settings. Therefore, it is necessary to develop, test, and disseminate disease-specific models of palliative care that can be successfully integrated into different cancer settings and organizational systems.
- Results from this study suggest that patients with metastatic NSCLC continue to experience high symptom burden and diminished physical well-being over time while receiving cancer treatments. A palliative care intervention consisting of an ICC is currently being tested for patients with NSCLC.

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## Disclosure

The authors have stated that they have no conflicts of interest.

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