



A Longitudinal Perspective of the Symptom Experience of Patients With Lung Cancer Near the End of Life

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Lung cancer patients' unrelieved symptoms are associated with poor quality of life. Understanding their symptoms can direct interventions to enhance quality of life. This longitudinal study explored the symptoms of patients with advanced lung cancer by examining changes in symptom frequency, severity, and distress and their relationship with quality of life and functional status. Eighty patients with advanced lung cancer were interviewed within 1 month of diagnosis and at 2- and 4-month follow-up periods. Fifty percent of patients died within 5 months of diagnosis. Patients reported less symptom frequency and severity over time but no significant changes in symptom distress. Lack of energy, pain, shortness of breath, cough, and difficulty sleeping were the most common symptoms. The patients reported increased pain frequency, decreased severity in sleeping difficulties, and decreased distress related to shortness of breath. The 11 most commonly occurring symptoms were inversely related to quality of life. Five of these symptoms were negatively associated with functional status. Although symptom prevalence and severity decreased over time, symptom distress did not. Frequent and ongoing symptom assessment that includes perceived distress is paramount to direct interventions to enhance quality of life and functional status of patients with advanced lung cancer.

Lung cancer is the leading cause of cancer death for men and women worldwide.¹ The majority of patients with lung cancer received the diagnosis at an advanced stage^{2,3} and, despite treatment, often progress rapidly to the end of life (EOL). Goals of care for patients with advanced lung cancer include decreasing symptom burden and increasing quality of life (QOL).⁴ Unrelieved symptoms, common in the cancer population, are associated with decreased QOL.⁵ Symptom control is a necessary component of care to decrease suffering and improve patients' QOL. It is essential for nurses to understand the symptom experience of patients with lung cancer throughout the cancer trajectory and to intervene to improve patients' QOL.

Cancer patients in general experience a multitude of symptoms resulting from both underlying disease and treatment.⁶ Patients with lung cancer often experience an even higher symptom burden than do patients with other types of cancer,⁷ and these symptoms are often difficult to treat.⁸ Symptoms most commonly reported by patients with lung cancer include fatigue, pain, dyspnea, cough, difficulty sleeping, and anorexia.^{9,10} Symptoms vary depending on stage of disease and treatment; however, it is clear that patients with lung cancer experience a large number of symptoms that negatively affect their QOL¹¹⁻¹³ and survival.¹⁴ The number of symptoms patients experience is strongly associated with greater psychological distress and lower QOL; however, it is important to note that the most frequent or intense symptom may not be the most distressing. Symptom distress rather than frequency or severity may most accurately reflect patients' QOL.^{15,16} Symptom distress is the degree of physical or mental upset, suffering, or anguish reported by the patient as a result of specific symptoms.¹⁷ Because of the effect of symptom distress on QOL, patient assessment must include not only symptom presence and severity, but also associated distress.

Patients may experience different symptoms as their disease progresses. Therefore, it is important for nurses to understand their symptoms throughout the course of the disease in order to intervene to improve patients' QOL. The majority of studies that have examined the symptoms experienced by patients near the EOL, and patients with advanced lung cancer specifically, have been cross-sectional.

KEY WORDS

end of life, lung cancer, palliative care, quality of life, symptoms

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The purpose of this study was to longitudinally explore the symptom experience of patients with advanced lung cancer near the EOL. The specific aims were to (1) examine changes in symptom frequency, severity, and distress over a 4-month period; (2) identify changes in patients' most problematic symptoms; and (3) examine the relationships of patients' most problematic symptoms with QOL and functional status.

METHODS

Design

Data for this longitudinal study were collected via patient interview and medical record review at baseline and at 2- and 4-month follow-up periods. Findings from this project related to determinants of QOL were published previously.¹⁸

Setting and Sample

Patients with advanced lung cancer were recruited from a research and treatment cancer center and 2 private oncology offices. Eligibility criteria included new diagnosis in the previous month with stage IIIB or IV lung cancer or a diagnosis of recurrent lung cancer with distant disease, 18 years or older, English speaking, residing within a 150-mile radius of the cancer center, and passing the Short Portable Mental Status Questionnaire.¹⁹

Measures

Memorial Symptom Assessment Scale (MSAS). The MSAS¹⁵ is a self-report instrument that assesses 32 symptoms common to persons with cancer. Twenty-four symptoms are assessed for frequency (1 = rarely to 4 = almost constantly), severity (1 = slight to 4 = very severe), and distress (0 = not at all to 4 = very much); severity and distress only are assessed for the remaining 8. The Global Distress Index, considered to be a measure of overall symptom distress, is calculated using the average frequency of 4 common psychological symptoms (feeling sad, worrying, feeling irritable, feeling nervous) and the average distress of 6 common physical symptoms (lack of appetite, lack of energy, pain, feeling drowsy, constipation, dry mouth).

This study examined changes over time in the frequency, severity, and distress associated with each symptom. In addition, we calculated means for frequency, severity, and distress for all symptoms, as well as an "overall MSAS score" for each symptom, defined for each patient as the mean of the MSAS frequency, severity, and distress scores for that patient. Note that frequency was not included in any of these calculations for the 8 symptoms that were evaluated only for severity and distress in the MSAS. Finally, we defined the "total MSAS score" for each patient as the average of the "overall MSAS scores" for all 32 symptoms. The validity of the

MSAS has been supported by strong correlations with clinical status and QOL. Cronbach's α reliabilities were .83 to .88 in this sample.

Hospice Quality of Life Index (HQLI). The HQLI²⁰ is a 28-item self-report instrument that measures psychophysiological well-being, functional well-being, and social/spiritual well-being. Each item has a numeric rating scale (0 = lowest QOL to 10 = highest QOL). The range of total scores is 0 to 280; a higher score indicates a higher QOL. The HQLI differentiated between hospice patients and control subjects. All subscale α 's were .84, and the total scale α was .88 in this sample. This scale has been used extensively with cancer patients at the EOL.

Karnofsky Performance Status Scale (KPS). The KPS²¹ was used to assess functional status on a scale of 100 (asymptomatic, normal function) to 0 (dead). The reliability and validity of the KPS as a measure of functional status in patients with advanced cancer have been demonstrated.²²

Demographic and Medical Characteristics. At baseline, each patient self-reported age, race, gender, marital status, education, employment status, income, and religious preference. Variables collected via chart review at each data point included lung cancer stage, time since diagnosis, treatment stage (newly diagnosed, active treatment with progression, palliation), current treatment (radiation, chemotherapy, none), time since last treatment, supportive care received (hospice, home health), and comorbid conditions.

Procedure

This study was approved by the university institutional review board. Informed consent was obtained prior to data collection. Patients meeting the inclusion criteria were interviewed for responses to a series of standardized instruments to assess demographic, physical, psychosocial, and spiritual characteristics. Baseline data were collected from the patient where they were receiving oncology care. Data collection at 2 and 4 months took place in the patient's home. Medical records were reviewed at baseline and at 2 and 4 months for data on medical characteristics.

Statistical Analysis

The longitudinal data were summarized using the area under the curve (AUC). For each subject and outcome measure, the AUC combines the results at all 3 time points into an overall value of the measure over the course of the study for that subject. Mixed-effects regression models were used when comparing mean values of outcome measures across time points to make use of all available data. Pearson correlation was used to measure the associations among continuous variables, and point biserial r was used to measure the associations of continuous variables with dichotomous variables. Two-tailed tests with a significance level of .05 were used throughout. Continuous demographic and medical characteristics were summarized using mean (SD). The

clinical measures (MSAS score, etc) at each time point were summarized using mean \pm SE in order to account for the different sample sizes at baseline, 2 months, and 4 months. All analyses were performed using SAS 9.0 (SAS Institute, Inc, Cary, North Carolina).

RESULTS

The 80 patients who enrolled had a mean age of 61 (SD, 10) years. At 2 months, data were collected from 55 patients. At 4 months, data were collected from 41 patients. With 1 exception, all attrition was due to patient death. Complete demographic and medical characteristics of the sample have been reported previously.¹⁸ The majority was white and male and had stage IV lung cancer. Half the sample was married. Ninety-percent had newly diagnosed lung cancer within 1 month of study enrollment. The mean time since diagnosis was 23 (SD, 19) days. Chronic lung disease and hypertension were the most common comorbid conditions. At study enrollment, 99% of patients were receiving radiation, chemotherapy, or a combination. Only 3% enrolled in hospice during the study.

Mean symptom frequency was significantly higher at baseline than at either 2-month ($P = .036$) or 4-month ($P = .041$) follow-up periods (Table 1). For average symptom severity, the mean score was significantly higher at baseline than at 4 months ($P = .019$). There were no significant changes in mean symptom distress scores or on the Global Distress Index. For the total MSAS score, the mean score was significantly higher at baseline than at 4 months ($P = .028$). In addition to significant changes in MSAS-related measures, there were significant changes over time for the KPS: mean

functional status was significantly higher at baseline than at either 2 months ($P < .001$) or 4 months ($P < .001$). There were no significant differences in QOL scores over time.

Table 2 contains summary statistics for the AUC of the overall MSAS score for the 12 symptoms that had a mean AUC of 1.0 or greater for this overall score. (A score of 1.0 corresponds to “rarely” for frequency, “slight” for severity, and an intermediate value between “not at all” [scored 0.8] and “A little bit” [scored 1.6] for distress.) For this research, these 12 items are referred to as “the most frequently endorsed” of the 32 symptoms and are the only ones included in subsequent analyses.

Pain, dry mouth, and constipation were the only symptoms that significantly changed over time (Table 3). For pain, the mean overall score was significantly higher at 4 months than at 2 months ($P = .006$). For dry mouth and constipation, the mean overall score at 2 months was significantly lower than the mean score at baseline ($P = .004$ and $P = .006$, respectively). There were no other significant differences in mean overall score for any of the 12 most frequently endorsed symptoms. Pain and dry mouth were the only symptoms that changed significantly in mean frequency over time. For pain, the mean frequency score was significantly higher at 4 months than at 2 months ($P = .010$). For dry mouth, the mean frequency score at 2 months was significantly lower than the mean score at baseline ($P = .010$). There were no other significant differences in mean frequency score for any of the other most frequently endorsed symptoms. Note that the frequency of constipation is not assessed in the MSAS. Difficulty sleeping and constipation were the only symptoms that significantly changed in mean severity over time. For difficulty sleeping, the mean

TABLE 1 Changes in MSAS Scales, Quality of Life, and Functional Status Over Time

Variable	n ^a	Baseline ^b	2 mo ^b	4 mo ^b	AUC	P ^c
Total MSAS score	80	1.07 ^a \pm 0.49	0.96 \pm 0.51	0.88 ^b \pm 0.41	1.04 \pm 0.46	.034 ^d
Average symptom frequency	80	1.25 ^a \pm 0.55	1.10 ^b \pm 0.58	1.04 ^b \pm 0.49	1.20 \pm 0.51	.035 ^d
Average symptom severity	80	1.59 ^a \pm 0.53	1.48 \pm 0.53	1.33 ^b \pm 0.52	1.55 \pm 0.48	.025 ^d
Average symptom distress	80	2.48 \pm 0.52	2.43 \pm 0.58	2.37 \pm 0.63	2.47 \pm 0.49	.431
Global Distress Index	80	1.89 \pm 0.77	1.76 \pm 0.87	1.75 \pm 0.70	1.86 \pm 0.72	.469
Quality of life	80	6.95 \pm 1.44	6.97 \pm 1.46	7.02 \pm 1.58	6.91 \pm 1.35	.612
Functional Status (Karnofsky)	80	73.8 ^a \pm 12.4	67.3 ^b \pm 17.3	67.0 ^b \pm 19.1	68.8 \pm 12.6	<.001 ^d

Abbreviations: AUC, area under the curve; MSAS, Memorial Symptom Assessment Scale.

Summary statistics are given as mean \pm SE.

^aNumber of subjects with at least 1 observation for that measure.

^bMeans with different letters as superscripts are significantly different.

^cP value for change in the variable over the course of the study.

^dStatistically significant difference across the 3 time points ($P < .05$).



TABLE 2 Descriptive Statistics for Area Under the Curve for Total MSAS Score for the 12 Most Frequently Endorsed Symptoms

Symptom	n	Mean	SD
Lack of energy	80	2.74	1.13
Pain	79	2.15	1.15
Shortness of breath	80	1.96	1.18
Cough	80	1.71	1.05
Difficulty sleeping	79	1.68	1.30
Dry mouth	80	1.63	1.22
Feeling drowsy	79	1.62	1.13
Worrying	79	1.58	1.27
Lack of appetite	80	1.41	1.29
Feeling nervous	80	1.25	1.12
Feeling sad	80	1.15	1.11
Constipation	80	1.01	1.10

Abbreviation: MSAS, Memorial Symptom Assessment Scale.

severity score was significantly higher at baseline than at 2 months ($P = .0497$) and at 4 months ($P = .012$). For constipation, the mean severity score was significantly higher at baseline than at 2 months ($P = .002$). There were no other significant differences in mean severity score for any of the 12 most frequently endorsed symptoms. Shortness of breath was the only symptom that significantly changed in mean distress level over time; the mean score at 4 months was significantly lower than at baseline ($P = .010$) and at 2 months ($P = .015$).

The overall MSAS score for each of the 12 most frequently endorsed symptoms was examined for correlations with QOL and functional status (Table 4). The overall MSAS score was negatively correlated with QOL for all of the 12 most frequently endorsed symptoms except constipation. Five of the symptoms were negatively correlated with functional status as measured by the KPS.

DISCUSSION

This study provides a longitudinal view of the symptom experience of patients with advanced lung cancer, and for many individuals, from diagnosis to the EOL. Although patients were enrolled within 1 month of diagnosis of stage IIIB or IV lung cancer, almost 50% had died at the 4-month follow-up.

These patients had relatively low symptom frequency and severity scores, but even a mild symptom level is suf-

ficiently severe to disrupt daily activities.²³ The need for clinicians to recognize and comprehensively address symptoms is evident, even when symptoms are mild or moderate.¹² When patients are not yet experiencing symptoms, anticipatory management is needed. Patients should be taught to recognize commonly occurring symptoms and given resources to avert symptom onset or worsening. A key finding in this study is that patients reported fewer and less severe symptoms over time, but did not perceive a change in symptom distress. Symptom distress has been more closely associated with QOL than symptom frequency and severity.^{15,16} The findings of this study support other investigators' recommendations of using comprehensive tools that assess symptom distress in addition to presence and severity.²⁴ Identification of the symptoms causing patients the most distress can guide nurses in developing symptom treatment and patient education plans.²⁵

The most common symptoms in our sample included lack of energy, pain, shortness of breath, cough, and difficulty sleeping. Although the most common symptoms reported by patients vary somewhat among studies, our findings are consistent with those of other studies.^{9,26-28} An in-depth discussion of symptom management is beyond the scope of this report; however, evidence-based recommendations are available to guide health care professionals.^{29,30}

Fatigue is experienced by as many as 80% to 100% of patients with lung cancer.³¹ Lack of energy was the highest ranked symptom at every time point in this sample and was negatively correlated with QOL and functional status. Patients have reported fatigue to be the most distressing of all cancer-related symptoms.³² This study supports that finding. According to the National Comprehensive Cancer Network guidelines,³³ fatigue should be assessed during the first clinic visit and routinely thereafter. Once identified, comprehensive assessment is needed to identify underlying causes. In the absence of identifiable causes, symptomatic treatment becomes the primary goal. Addressing fatigue is important for improving QOL, functional status, and, possibly, survival.^{14,33}

In our sample, pain levels initially decreased after diagnosis but rose significantly at 4 months. Increased pain as patients near the EOL is supported by others.³⁴ The effects of pain on QOL is well documented and is the symptom most feared by patients.³⁵ The lack of a relationship between pain and functional status was surprising, considering others have reported a relationship.²³ The lack of relationship may be attributed to the high attrition rate, in that the most ill patients died before study completion. Not only is pain control important for maximizing QOL, but also for controlling costs, as pain has been associated with higher emergency room usage.³⁶ Practice guidelines for cancer pain management indicate pain should be assessed at each patient contact. When pain is ongoing, a comprehensive

TABLE 3 Changes in the 12 Most Frequently Endorsed Symptoms Over Time (Frequency, Severity, and Distress, Combined)

Symptom	n ^a	Baseline ^b	2 mo ^b	4 mo ^b	AUC	P ^c
Lack of energy	80	2.70 ± 0.14	2.75 ± 0.17	2.81 ± 0.17	2.74 ± 0.13	0.876
Pain	79	2.05 ± 0.16	1.85 ^a ± 0.18	2.44 ^b ± 0.20	2.15 ± 0.13	0.021 ^d
Shortness of breath	80	1.92 ± 0.15	1.98 ± 0.19	1.77 ± 0.19	1.96 ± 0.13	0.627
Cough	80	1.71 ± 0.14	1.65 ± 0.19	1.59 ± 0.18	1.71 ± 0.12	0.839
Difficulty sleeping	79	1.88 ± 0.17	1.36 ± 0.19	1.50 ± 0.22	1.68 ± 0.15	0.067
Dry mouth	80	1.77 ^a ± 0.15	1.25 ^b ± 0.16	1.44 ± 0.20	1.63 ± 0.14	0.018 ^d
Feeling drowsy	79	1.60 ± 0.15	1.70 ± 0.18	1.29 ± 0.19	1.62 ± 0.13	0.242
Worrying	79	1.64 ± 0.17	1.33 ± 0.19	1.67 ± 0.22	1.58 ± 0.14	0.299
Lack of appetite	80	1.52 ± 0.17	1.24 ± 0.21	1.19 ± 0.24	1.41 ± 0.14	0.383
Feeling nervous	80	1.21 ± 0.14	1.20 ± 0.16	1.17 ± 0.20	1.25 ± 0.13	0.986
Feeling sad	80	1.11 ± 0.14	1.27 ± 0.17	1.03 ± 0.16	1.15 ± 0.12	0.530
Constipation	80	1.22 ^a ± 0.16	0.66 ^b ± 0.16	0.82 ± 0.20	1.01 ± 0.12	0.025 ^d

Abbreviation: AUC, area under the curve.

Summary statistics are given as mean ± SE.

^aNumber of subjects with at least one observation for that symptom.

^bMeans with different letters as superscripts are significantly different.

^cP value for change in the variable over the course of the study.

^dStatistically significant difference across the 3 time points ($P < .05$).

assessment that includes the impact of pain on the patient should be performed regularly.³⁵

Shortness of breath was common in these patients and significantly affected QOL and functional status. Changes in shortness of breath were not seen when frequency, severity, and distress scores were combined over all time periods; however, when distress alone was examined over time, there was a significant decrease from baseline to 4 months. The vast majority were receiving treatment during the study. Although patients did not perceive less frequent or severe shortness of breath, their distress decreased. Perhaps patients received interventions focused on coping with dyspnea that resulted in decreased distress. It is important to recognize dyspnea is subjective; therefore, self-report is essential. Lai and colleagues³⁷ indicated the terms *dyspnea*, *shortness of air*, and *breathlessness* may not be understood by all patients, and exploration of specific symptoms and sensations may be necessary. This study assessed dyspnea as a total concept by asking patients how often they experienced “shortness of breath” in the past week. Differentiation between persistent and episodic dyspnea was not made. Patients with advanced cancer may experience “breakthrough” or episodic dyspnea more frequently than persistent/continuous dyspnea,³⁸ and intervention should vary depending on the type of dyspnea.³⁹ Because of the

effects of dyspnea on QOL and functional status, thorough assessment is necessary to tailor interventions to the specific type of dyspnea.

Cough is consistently reported as a common and distressing symptom in patients with lung cancer. Our findings agree. Cough negatively affected patients’ QOL but not functional status. In a longitudinal study of patients with lung cancer, cough played a significant part in symptom experience and significantly affected QOL.¹³ As with dyspnea, there are varying etiologies of cough, and a complete assessment for type, pattern, precipitating/relieving factors, and underlying comorbidities is necessary.

Sleep difficulties are common in patients with lung cancer.^{5,12} Our patients reported difficulty sleeping and feeling drowsy, which negatively impacted QOL. Previous studies have also found sleep disturbances negatively impact QOL.¹² The presence of physical symptoms (pain, fatigue, shortness of breath, cough) along with psychological symptoms (worrying, feeling nervous, feeling sad) could account for the sleep disturbances.

While not in the top 5, it is important to note that 3 of the 12 most frequently endorsed symptoms were psychological in nature—worrying, feeling nervous, and feeling sad. These symptoms did not change over time and were negatively correlated with QOL. Both patients



TABLE 4 Correlations of Overall MSAS Score for the 12 Most Frequently Endorsed Symptoms With Quality of Life and Functional Status

Symptom	QOL	Functional Status
Lack of energy	-0.49 ^a	-0.43 ^a
Pain	-0.33 ^b	NS
Shortness of breath	-0.46 ^a	-0.30 ^b
Cough	-0.30 ^b	NS
Difficulty sleeping	-0.56 ^a	NS
Dry mouth	-0.44 ^a	-0.46 ^a
Feeling drowsy	-0.28 ^b	-0.22 ^b
Worrying	-0.67 ^a	NS
Lack of appetite	-0.53 ^a	NS
Feeling nervous	-0.54 ^a	-0.28 ^b
Feeling sad	-0.59 ^a	NS
Constipation	NS	NS

Abbreviations: MSAS, Memorial Symptom Assessment Scale; NS, not statistically significant; QOL, quality of life.
Sample size varies from 79 to 80.
^a*p* < .001.
^b*p* < .05.

with early- and those with late-stage lung cancer have identified the symptoms of worry and fear as their most salient educational need, surpassing all other symptoms and topics in the physical, social, spiritual, and psychological categories of well-being.⁴⁰ Perhaps this reflects the universal phenomenon of patients and their struggle to cope with cancer. In addition, this may highlight the lack of attention that psychological issues receive in the clinical setting. Psychological evaluation is frequently not a standard part of patient assessment. Our findings underscore the need to assess and intervene for psychological symptoms along with symptoms that are physical in nature. Evidence exists as to the positive effect of structured communication such as family meetings on the psychological well-being of patients and caregivers.⁴¹ Incorporating family meetings throughout the cancer trajectory may be an effective strategy to decrease worry and fear in patients with lung cancer.

Even with the high mortality rate, only 3% received hospice care. This may have occurred for various reasons. Patients with advanced lung cancer may be near the EOL at diagnosis but undergoing treatments that make them ineligible for hospice benefits. Development and testing of

models of EOL care appropriate for individuals receiving treatment, yet progressing toward death, are needed. Perhaps hospice enrollment was low because health care professionals did not present hospice as an option to patients and caregivers. Another reason may be that patients and caregivers believe hospice care hastens death; however, hospice care has not been found to decrease survival in patients with advanced lung cancer.⁴² Given that patients with lung cancer dying in a hospital experience higher pain levels and burden than patients dying at home,²⁶ additional efforts at enrolling patients in hospice earlier may be warranted. Goals-of-care discussions among the patient, family, and treatment team should occur frequently and include hospice as an option, as appropriate.

Limitations

Longitudinal data collection with patients with advanced cancer presents many challenges. A major limitation of this study was the high attrition rate. Attrition could have affected the number of reported symptoms as well as QOL and functional status ratings, as it is expected the most severely ill patients died. Data were collected every 2 months, but because patients' health declined so rapidly, a complete and accurate symptom experience may not have been obtained. More frequent data collection points to enrich the description of the symptom experience were needed. The study was conducted in 1 geographic location of the United States; thus, generalization to all patients with lung cancer cannot be made. In addition, the relatively homogenous sample in relation to race limits generalizability. Greater representation of minorities would increase the ability to generalize to all patients with advanced lung cancer. Patients were not being seen by a palliative care team; therefore, results may be different with patients receiving formal palliative care.

Implications for Nursing

These study results have important implications for nursing education, practice, and research. In formal nursing education as well as continuing education, emphasis must be placed on the essential role that nurses play in symptom assessment and management. Information on evidence-based interventions for symptom management should be provided. In the clinical practice setting, nurses are the team members who typically spend the greatest amount of time with patients and are in a key position to assess for the wide variety of symptoms experienced by cancer patients. It is imperative that nurses use an assessment tool that includes a comprehensive list of symptoms, as there is great variability in the symptoms that patients experience. Patients may not recognize things such as fatigue or worry as symptoms that can be managed. They may believe their symptoms are expected and unavoidable outcomes of cancer and/or treatment and may not report



them if not asked about them specifically. Broad questions by the nurse such as “What is bothering you?” or “What symptoms are you experiencing?” may lead to an underreporting of symptoms and thus inadequate symptom management. The findings demonstrate the importance of assessing the distress patients perceive with symptoms and not merely focusing on frequency and severity. Research that tests the effectiveness of interventions aimed at decreasing symptom distress is needed.

This study underscores the importance of recognizing that patients with advanced lung cancer may be near the EOL upon diagnosis. Nurses are an integral part of the interdisciplinary team that should be conducting conversations with patients and caregivers regarding prognosis and goals of care. Therefore, nurses should provide education on available resources including palliative care and hospice. The value of beginning palliative care for patients with advanced lung cancer at the time of diagnosis has been supported,²⁷ and nurses should advocate for this in the clinical setting. Palliative care using a holistic approach to symptom assessment and management that involves all members of the interdisciplinary team has led to improved QOL for patients. Additional studies testing interdisciplinary approaches, such as palliative care teams, for complex symptom management are needed.

CONCLUSIONS

This study expands our understanding of the symptom experience of patients with advanced lung cancer. Patients are often symptomatic upon diagnosis. Palliative care received early during treatment of advanced lung cancer increases QOL, mood, and survival and decreases emergency room and intensive care unit care when compared with standard oncologic care.³⁴ Therefore, prompt and frequent attention to symptom management is essential. The first step in symptom management is a comprehensive assessment of patient symptoms including symptoms that are psychological in nature. Because symptom distress may remain unchanged even with decreasing number and severity of symptoms, it is paramount for nurses to assess patients' symptom distress. As patients near the EOL, the primary objective of care is to maintain or improve QOL. Frequent and ongoing symptom assessment that includes perceived distress is essential to direct interventions to enhance QOL and functional status of patients with advanced lung cancer.

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References

1. International Agency for Research on Cancer (IARC). GLOBOCAN 2012: estimated cancer incidence and prevalence

- and mortality worldwide in 2012. 2015. http://globocan.iarc.fr/Pages/fact_sheets_cancer.aspx. Accessed August 4, 2015.
2. National Comprehensive Cancer Network (NCCN). Small cell lung cancer. Version 1.2016. 2015. http://www.nccn.org/professionals/physician_gls/pdf/sclc.pdf. Accessed August 4, 2015.
3. National Comprehensive Cancer Network (NCCN). Non-small cell lung cancer. Version 7.2015. 2015. http://www.nccn.org/professionals/physician_gls/pdf/nscl.pdf. Accessed August 4, 2015.
4. Ford DW, Koch KA, Ray DE, Selecky PA. Palliative and end-of-life care in lung cancer: diagnosis and management of lung cancer, 3rd ed. American College of Chest Physicians evidence-based clinical practice guidelines. *Chest*. 2013;143(5 suppl):e498S-e512S.
5. Franceschini J, Jardim JR, Fernandes AL, Jamnik S, Santoro IL. Relationship between the magnitude of symptoms and the quality of life: a cluster analysis of lung cancer patients in Brazil. *J Bras Pneumol*. 2013;39(1):23-31.
6. Reilly CM, Bruner DW, Mitchell SA, et al. A literature synthesis of symptom prevalence and severity in persons receiving active cancer treatment. *Support Care Cancer*. 2013;21(6):1525-1550.
7. Shi Q, Smith TG, Michonski JD, Stein KD, Kaw C, Cleeland CS. Symptom burden in cancer survivors 1 year after diagnosis: a report from the American Cancer Society's Studies of Cancer Survivors. *Cancer*. 2011;117(12):2779-2790.
8. Alt-Epping B, Stäritz AE, Simon ST, et al; Hospice and Palliative Care Evaluation Hope Working Group. What is special about patients with lung cancer and pulmonary metastases in palliative care? Results from a nationwide survey. *J Palliat Med*. 2012;15(9):971-977.
9. Cleeland CS, Mendoza TR, Wang XS, et al. Levels of symptom burden during chemotherapy for advanced lung cancer: differences between public hospitals and a tertiary cancer center. *J Clin Oncol*. 2011;29(21):2859-2865.
10. Yang P, Cheville AL, Wampfler JA, et al. Quality of life and symptom burden among long-term lung cancer survivors. *J Thorac Oncol*. 2012;7(1):64-70.
11. Iyer S, Taylor-Stokes G, Roughley A. Symptom burden and quality of life in advanced non-small cell lung cancer patients in France and Germany. *Lung Cancer*. 2013;81(2):288-293.
12. Liao Y-C, Shun S-C, Liao W-Y, Yu C-J, Yang P-C, Lai Y-H. Quality of life and related factors in patients with newly diagnosed advanced lung cancer: a longitudinal study. *Oncol Nurs Forum*. 2014;41(2):E44-E55.
13. Molassiotis A, Lowe M, Blackhall F, Lorigan P. A qualitative exploration of a respiratory distress symptom cluster in lung cancer: cough, breathlessness and fatigue. *Lung Cancer*. 2011; 71(1):94-102.
14. Cheville AL, Novotny PJ, Sloan JA, et al. The value of a symptom cluster of fatigue, dyspnea, and cough in predicting clinical outcomes in lung cancer survivors. *J Pain Symptom Manage*. 2011;42(2):213-221.
15. Portenoy RK, Thaler HT, Kornblith AB, et al. The Memorial Symptom Assessment Scale: an instrument for the evaluation of symptom prevalence, characteristics and distress. *Eur J Cancer*. 1994;30A(9):1326-1336.
16. Garrison CM, Overcash J, McMillan SC. Predictors of quality of life in elderly hospice patients with cancer. *J Hosp Palliat Nurs*. 2011;13(5):288-297.
17. Rhodes VA, Watson PM. Symptom distress—the concept: past and present. *Semin Oncol Nurs*. 1987;3(4):242-247.
18. Hermann CP, Looney SW. Determinants of quality of life in patients near the end of life: a longitudinal perspective. *Oncol Nurs Forum*. 2011;38(1):23-31.
19. Pfeiffer E. A Short Portable Mental Status Questionnaire for the assessment of organic brain deficit in elderly patients. *J Am Geriatr Soc*. 1975;23(10):433-441.



20. McMillan SC, Weitzner M. Quality of life in cancer patients: use of a revised Hospice Index. *Cancer Pract*. 1998;6(5):282-288.
21. Karnofsky DA, Burchenal JH. The clinical evaluation of chemotherapeutic agents in cancer. In: MacLeod CM, ed. *Evaluation of Chemotherapeutic Agents*. New York: Columbia Univ Press; 1949:191-205.
22. Yates JW, Chalmer B, McKegney FP. Evaluation of patients with advanced cancer using the Karnofsky Performance Status. *Cancer*. 1980;45(8):2220-2224.
23. Tanaka K, Akechi T, Okuyama T, Nishiwaki Y, Uchitomi Y. Impact of dyspnea, pain, and fatigue on daily life activities in ambulatory patients with advanced lung cancer. *J Pain Symptom Manage*. 2002;23(5):417-423.
24. Mcmillan SC, Toftagen C, Choe R, Rheingans J. Assessing symptoms experienced by patients with cancer. *J Hosp Palliat Nurs*. 2015;17(1):56-65.
25. Stark L, Toftagen C, Visovsky C, McMillan SC. The symptom experience of patients with cancer. *J Hosp Palliat Nurs*. 2012; 14(1):61-70.
26. Barbera L, Paszat L, Qiu F. End-of-life care in lung cancer patients in Ontario: aggressiveness of care in the population and a description of hospital admissions. *J Pain Symptom Manage*. 2008;35(3):267-274.
27. Temel JS, Jackson VA, Billings JA, et al. Phase II study: integrated palliative care in newly diagnosed advanced non-small-cell lung cancer patients. *J Clin Oncol*. 2007;25(17):2377-2382.
28. Genç F, Tan M. Symptoms of patients with lung cancer undergoing chemotherapy and coping strategies. *Cancer Nurs*. 2011;34(6): 503-509.
29. Simoff MJ, Lally B, Slade MG, et al. Symptom management in patients with lung cancer. *Chest*. 2013;143(5 suppl):e455S-e497S.
30. Ferrell BR, Coyle N, Paice J eds. *Oxford Textbook of Palliative Nursing*. 4th ed. Oxford: Oxford University Press; 2015.
31. Iyer S, Roughley A, Rider A, Taylor-Stokes G. The symptom burden of non-small cell lung cancer in the USA: a real-world cross-sectional study. *Support Care Cancer*. 2014;22(1):181-187.
32. Butt Z, Rosenbloom SK, Abernethy AP, et al. Fatigue is the most important symptom for advanced cancer patients who have had chemotherapy. *J Natl Compr Canc Netw*. 2008;6(5):448-455.
33. National Comprehensive Cancer Network (NCCN). NCCN clinical practice guidelines in oncology. Cancer-related fatigue. Version 2.2015. 2015. http://www.nccn.org/professionals/physician_gls/pdf/fatigue.pdf. Accessed August 4, 2015.
34. Temel JS, Greer JA, Admane S, et al. Early palliative care for patients with metastatic non-small-cell lung cancer. *J Clin Oncol*. 2011;29(17):2319-23262.
35. National Comprehensive Cancer Network (NCCN). NCCN clinical practice guidelines in oncology. Adult cancer pain. Version 2.2015. 2015. http://www.nccn.org/professionals/physician_gls/pdf/pain.pdf. Accessed August 4, 2015.
36. Mayer DK, Travers D, Wyss A, Leak A, Waller A. Why do patients with cancer visit emergency departments? Results of a 2008 population study in North Carolina. *J Clin Oncol*. 2011;29(19): 2683-2688.
37. Lai YL, Chan CW, Lopez V. Perceptions of dyspnea and helpful interventions during the advanced stage of lung cancer: Chinese patients' perspectives. *Cancer Nurs*. 2007;30(2):E1-E8.
38. Reddy SK, Parsons HA, Elsayem A, Palmer JL, Bruera E. Characteristics and correlates of dyspnea in patients with advanced cancer. *J Palliat Med*. 2009;12(1):29-36.
39. Simon ST, Weingärtner V, Higginson IJ, Voltz R, Bausewein C. Definition, categorization, and terminology of episodic breathlessness: consensus by an international Delphi survey. *J Pain Symptom Manage*. 2014;47(5):828-838.
40. Borneman T, Sun V, Williams AC, et al. Support for patients and family caregivers in lung cancer. *J Hosp Palliat Nurs*. 2015;17(4): 309-318.
41. Sullivan SS, da Rosa Silva CF, Meeker MA. Family meetings at end of life. A systematic review. *J Hosp Palliat Nurs*. 2015;17(3):196-205.
42. Saito AM, Landrum MB, Neville BA, Ayanian JZ, Weeks JC, Earle CC. Hospice care and survival among elderly patients with lung cancer. *J Palliat Med*. 2011;14(8):929-939.

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