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Assessment and Management of Symptoms for Outpatients Newly Diagnosed with Lung Cancer

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Abstract

Rationale—Little is known about symptom assessment around the time of lung cancer diagnosis. The purpose of this pilot study was to assess symptoms within 2 months of diagnosis and the frequency with which clinicians addressed symptoms among a cohort of Veterans (n=20) newly diagnosed with lung cancer. We administered questionnaires then reviewed medical records to identify symptom assessment and management provided by subspecialty clinics for 6 months following diagnosis.

Results—Half of patients (50%) were diagnosed with early stage non-small cell lung cancer (NSCLC), stage I or II. At baseline, 45% patients rated their overall symptoms severe. There were no significant differences in symptoms among patients with early or late stage NSCLC or small cell lung cancer. Of the 212 clinic visits over 6 months, 70.2% occurred in oncology. Clinicians most frequently addressed pain, although assessment differed by clinic.

Conclusions—Veterans with newly diagnosed lung cancer report significant symptom burden. Despite ample opportunities to address patients' symptoms, variations in assessment exist among subspecialty services. Coordinated approaches to symptom assessment are likely needed among patients newly diagnosed with lung cancer.

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Keywords

lung cancer; newly diagnosed; symptom assessment; management

Introduction

Lung cancer is the second leading cause of life loss and the fourth leading cause of disability highlighting the enormous effect of lung cancer on patient's health and functional status.¹ Lung cancer has significant deleterious effects on mental well-being and demonstrates a magnitude of physical symptom burden that is highly debilitating²⁻⁴ and fluctuates with treatments and disease progression and over time.⁵⁻⁹ Symptom assessment is often performed well into treatment, and not necessarily at the time of diagnosis when patients may be symptomatic and need palliative care services. Surprisingly, there is little data available about the burden of symptoms that may be attributable to patients with lung cancer near the time of their diagnosis. We performed a pilot cohort study to examine the symptoms of patients recently diagnosed with lung cancer and whether these symptoms were assessed and treated when seen by clinicians. Our goal was to identify patients' symptoms early after diagnosis of lung cancer and examine patterns of care among outpatient subspecialty providers.

Methods

Design

We examined baseline data collected from a cohort of patients newly diagnosed with lung cancer within two months of the date of entry to the study. We followed patients for six months after their initial diagnosis.

Settings and subjects

Between March 2011 to October 2011, at the Veterans Affairs Puget Sound Health Care System in Seattle, WA, we screened patients newly diagnosed with lung cancer from our weekly Tumor Board meeting. We confirmed the diagnosis of lung cancer by reviewing information contained in their health records. Patients were excluded from participation if their diagnosis was confirmed longer than two months, unable to understand English, could not participate in the informed consent process or were already enrolled in palliative care or hospice services. After mailing an invitation, patients were contacted by phone and those who expressed interest had an in-person interview to provide informed consent and administer study questionnaires.

Measures

Patients completed the following surveys at the time of enrollment: 1) Symptom Distress Scale¹⁰ (SDS); 2) Quality of Clinicians' Communication Skills¹¹ (QOC); 3) Karnofsky's Functional Scale¹² and 4) demographic information including age, gender, ethnicity/culture, education, marital status, smoking status and co-morbidities.

Symptoms

The Symptom Distress Scale (SDS) consists of 13 symptoms.² Each symptom is rated on a 5-point likert scale ranging from 1 (normal or no distress) to 5 (severe distress), a rating >3 defines symptoms as severe. The SDS is scaled from 13-65 with 3 categories: mild overall symptoms (13-24); moderate overall symptoms (25-32); and severe overall symptoms 33.^{2,10,13-15}

Quality of communication about end-of-life care: We used the validated Quality of Communication (QOC) questionnaire end-of-life subscale to assess the frequency and quality of the clinician's communication skills as perceived by the patient.¹¹ We instructed patients to answer the questions in reference to the clinician who was primarily responsible for managing their lung cancer.

Travel burden

We calculated the number of round trip miles for each patient traveling from their place of residence to the VA Medical Center for each clinic visit over the six month time period.

Symptom based treatments

We abstracted the following information by reviewing notes from four subspecialty clinics including oncology, radiation oncology, pulmonary, and cardiothoracic surgery: 1) the type of symptoms assessed by specialists and 2) management of symptoms, both pharmacologic and non-pharmacologic. In addition, we collected referrals to ancillary services such as social services. The VA Puget Sound Health Care System Institution Review Board approved this protocol #00341. Informed consent was obtained from all subjects prior to data collection.

Analysis

We examined means (sd), and proportions of the cohort for demographic variables and health related variables. We used standard scoring for all questionnaires. We conducted a Kruskal-Wallis test to examine differences among patients' self-reported symptoms at baseline and the type and stage of lung cancer. The level of significance was set at $p = 0.05$.

Results

Patient Characteristics

We screened 122 patients of which 46 were excluded for not having a confirmed primary diagnosis of lung cancer ($n=28$), diagnosis was made more than 2 months prior to identification ($n=10$) or they enrolled in hospice or died ($n=4$). Seventy six patients were eligible and approached to participate in the study. Fifty-six declined to participate due to concern about travel distance and time to the VA ($n=35$, 62.5%), expressed they were too tired due to cancer treatments ($n=12$, 21.4%) and 9 (16.1%) patients did not offer a reason. The time between initial diagnosis and interview was 1.5 months. The patient cohort was comprised of mostly older (mean age, 63.2 years, SD 7.5), white men, the majority of whom had non-small-cell lung cancer (NSCLC). Of the 17 (85%) patients with NSCLC, 50% were diagnosed at Stage I-II, while 35% were diagnosed at Stages III-IV (Table 1).

Nearly half of the Veterans (45% n=9) rated their overall symptoms as severe on the SDS. Over half of the patients (65%, n=13) reported they experienced pain several times a week. In addition to complaints of pain, 40% (n=8) of patients reported having frequent or constant trouble breathing, and 55% (n=11) of patients reported they felt tired or exhausted most of time. There were no statistically significant differences in self-reported symptoms at baseline among patients with NSCLC stage I-II, NSCLC stage III-IV or SCLC (Table 2). The mean Karnofsky score reported by the patients was 73.5 (15.3 sd), demonstrating on average that they were able to care for themselves but unable to carry on all normal activity or engage in active work.

Patients rated the frequency and quality of clinicians' end-of-life communication skills poorly. Table 3 shows the percentage of subjects reporting the topic was addressed by the clinician primarily responsible for their lung cancer care. Two topics: *talking about what dying may be like* and *asking about your spiritual or religious beliefs* were addressed in only 4 (20%) patients. One of the questionnaire items related to *discussing prognosis* was either not addressed by clinicians or was addressed in the worst possible way among 60% of the subjects.

Symptom assessment conducted by subspecialty clinics over the 6-month period following diagnosis is shown in Table 4. Pain was assessed in all patients with oncology specialists performing this assessment most frequently (95%) followed by radiation oncology (78%), and surgery (78%) and pulmonary (63%). Dyspnea was assessed in 80% of the patients and was assessed most frequently by pulmonary specialists (63%). Anxiety and depression were assessed the least often (50% and 35% respectively) and when assessed, it was by oncology and radiation oncology specialists. Most patients regardless of cancer type or stage were seen most often by oncology specialists.

Symptom management consisted of prescribing new medications (13.7%), changing existing medications (10.3%) or documenting the current pharmacologic treatment was adequate (47%) at the time. Providers newly prescribed opioids for pain or dyspnea management for 11 (55%) of the patients. When new prescriptions were prescribed, they were prescribed the same day as the clinic visit. Non-pharmacologic treatments such as physiotherapy were ordered 9.4% of the time and consults such as social service or pain clinic occurred 23% of the time. We identified 23 encounters where symptoms were identified as bothersome but no management plan was documented. Of those 23 encounters the most common symptom identified was fatigue (43.4%). There were no consults to palliative care services and one referral to hospice.

Patients travelled on average 165 miles per round trip (230.8 SD) miles to the VA Medical Center and averaged 10 (range 1-20) outpatient clinic appointments over the 6-month follow up period. The primary reason patients travelled to the VA was for chemotherapy or radiation therapy. Two patients lived outside the state of WA and resided in temporary housing offered at the VA for the duration of their radiation treatment therefore zero distance was calculated.

Discussion

We found that Veterans with newly diagnosed lung cancer, regardless of type or stage, experience significant symptoms and have a large number of outpatient visits in the first six months. Our results suggest that despite the number of frequent visits, there were large variation of symptom assessment by subspecialty service. Pain was the most frequently addressed symptom and most consistently addressed by oncology service. This finding may be due to the high number of oncology clinic visits. Depression and anxiety were the least addressed symptoms and when addressed it was by oncology and radiation oncology services only. Our findings highlight that providers assess symptoms that are most prevalent in their subspecialties, for example, oncologists assess pain and pulmonologists assess dyspnea. Although believable en face, identification of these patterns present an opportunity to a deliver a more coordinated approach to symptom assessment for patients with newly diagnosed lung cancer.

Our study findings, which include patients diagnosed with early stage lung cancer, support previous studies reporting barriers to adequate symptom management including nonsystematic symptom assessment. A recent study describing symptom prevalence and severity within 3-6 months of diagnosis among patients with early or late stage lung cancer reported no differences between the two groups.¹⁶ Studies have found at the time of diagnosis, many patients with advanced lung cancer have symptoms from their lung cancer including fatigue, pain, cough, lack of appetite and insomnia with fatigue and pain remaining persistent.^{2,16,17} These symptoms are often complicated by co-existing conditions and the side effects from treatment for lung cancer adding to the complexity of symptom management.¹⁸ Patients with progressive cancer have a high prevalence of uncontrolled symptoms within 90 days of death, including advanced pain, dyspnea, fatigue, insomnia, decreased appetite and worry.¹⁹

We found that when symptoms were assessed they were addressed in a timely fashion across all specialties. New medications were generally prescribed on the same day as assessed and over one half of the patients were newly prescribed opioids. Providers made changes in existing medications and documented that treatment was adequate in almost one half of the patients. Timely management of patients' symptoms is a positive finding however utilization of ancillary services including social work and palliative care for patients with lung cancer could help address both physical and psychosocial needs. A recent qualitative study of patients' with lung cancer regarding their perceptions of palliative care visits showed that patients felt palliative care emphasized psychosocial elements whereas oncologic care visits focused on the cancer treatment and management of medical complications.²⁰

Studies have demonstrated positive outcomes from the delivery of palliative care services integrated into oncology care among patients with advanced cancers including improved quality of life, mood, care that is less directed at increasing the length of life, and longer survival.^{21 22 15 23} Among patients with stage IV lung cancer, Temel et al. found weekly assessments of symptoms in the outpatient setting accompanied by a palliative care team intervention not only improved quality of life and symptom burden, but also increased survival when compared to traditional approaches to treatment.²¹ Although palliative care

has known beneficial outcomes no patients in our study were referred to palliative care and one patient was referred for hospice care. A likely reason for the lack of palliative care referrals was at the time of the study the hospital did not have a formal outpatient palliative care clinic. However, a team of palliative care specialists were available for in-patient or case consultation.

We found patients rated the frequency and quality of clinicians' end-of-life communication skills poorly. Although it may not seem appropriate to discuss all end-of-life topics within the first 2 months of diagnosis, e.g. what dying may be like; important topics such as prognosis were not addressed. Under-addressing the topic of prognosis can lead to misconceptions about the goals of cancer treatment. Studies show the vast majority of patients desire information about their diagnosis, prognosis, and treatment options (88-99%) and most want to engage in end-of-life discussions (64%) although preferences about what is communicated varies.²⁴⁻²⁷ For example, some patients want all information about their prognosis including estimation of survival time, while others desire broader information about their prognosis and prefer to focus on quality versus quantity of life. Despite patients' desiring information about their prognosis, study findings consistently confirm discussing topics such as short life expectancy, palliative and end-of-life care are infrequently addressed by clinicians.^{24,28,29} A recent study exploring patients' perceptions of prognosis and goals of care in patients with advanced metastatic lung cancer found one third of patients reported their cancer was curable at baseline and a majority of patients reported getting rid of their cancer was a goal of therapy, indicating a poor understanding of their disease. Similar results were reported in a study investigating patients' expectation about chemotherapy for metastatic lung and colorectal cancer, despite patients rating their clinicians' communication as favorable.³⁰ In contrast, patients who received early palliative care had an accurate perception of their prognosis over time and received less chemotherapy near the end-of-life.³¹ Collectively these findings emphasize the importance of effective, coordinated patient-clinician communication, a component of high quality oncology care.

There are several strengths of this study. First, this is one of the few studies that enrolled patients shortly after a lung cancer diagnosis and followed prospectively for six months. Second, we included patients with any type and stage of lung cancer whereas previous studies have only focused on advanced NSCLC. Additionally, we used validated questionnaires and ascertained complete pharmacy records.

There are several limitations of our study. The surveys were administered once at baseline thus do not reflect changes over time. The survey used to assess symptoms may not have captured all symptoms the patients were experiencing thus resulting in underestimation of symptom burden. The generalizability of our findings is limited by a Veteran sample where patients often have multiple chronic conditions and psychosocial needs. The sample size was small which, though appropriate for a pilot study, may not remain consistent with a larger sample of patients and did not allow for robust comparison testing. However, our pilot study was hypothesis generating and supports a need for additional investigations in this area. Lastly, we only followed patients for 6 months however this time frame demonstrated abundant use of resource and patterns of care.

Conclusion

In summary, we found that Veterans with newly diagnosed lung cancer including early stage NSCLC and small cell, had significant symptom burden within the first six months of diagnosis and symptoms were inconsistently assessed by different subspecialty services. This supports the importance of developing processes or interventions to routinely assess and manage symptoms from the time of diagnosis to help improve long-term physical and psychosocial consequences. Integration of palliative care principles, which includes comprehensive symptom management and communication, into early oncologic care may provide a consistent coordinated approach to symptom assessment and management. Future direction includes testing novel interventions on the effect of integrating palliative care early after the diagnosis of lung cancer on patients' quality of life, symptom burden and satisfaction with care.

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Table 1

Patient Characteristics

Factors	Mean(SD) or % n=20
Age	63.2 (7.5)
FEV ₁ (% pred)	65.3 (18.3)
Male	95%
Married (n)	50%
Caucasian	90%
High School	70%
Smoking Status:	
Current	30%
Former	70%
Co-morbidities:	
COPD	30%
Arthritis	40%
Stages of cancer:	
NSCLC	85%
Stages 1-2	50%
Stages 3-4	35%
Small Cell	15%

Table 2

Baseline Patient-reported Symptom Distress Scale (n=20)

Symptom	NSCLC (stage 1-2) (n=10) M, SD	NSCLC (stage 3-4) (n=7) M, SD	Small Cell CA (n=3) M, SD	Total (n=20) M, SD
Pain	2.5 (.97)	2.9 (.69)	3.0 (1.7)	2.7 (.98)
Fatigue	2.6 (.70)	2.7 (1.3)	3.3 (1.2)	2.8 (.97)
Dyspnea	2.4 (.97)	2.4 (1.3)	2.3 (.58)	2.4 (.99)
Nausea	2.3 (1.4)	2.1 (1.1)	1.3 (.58)	2.1 (1.2)
Appetite	2.0 (.94)	2.1 (1.1)	2.3 (.58)	2.1 (.91)
Bowel	2.1 (.88)	2.1 (.90)	2.0 (1.0)	2.1 (.85)
Cough	2.6 (1.2)	2.9 (1.4)	1.7 (.58)	2.6 (1.2)
Insomnia	2.6 (1.7)	2.9 (1.2)	3.0 (1.0)	2.8 (1.4)

Range 1-5: 1=no problem, 5= maximum problem. > 3= severe symptoms

No statistical differences were found in symptoms among the 3 cancer stages and types.

* All variables were tested using the Kruskal-Wallis test for significance at p 0.05 level.

Table 3
Clinicians' End-of-Life Communication

Percentage of subjects reporting the topic was addressed by the clinician responsible for their lung cancer care.

End-of-Life Communication Items	Percentage of Patients reporting the topic was addressed
Talking about your feelings concerning getting sicker	30%
Talking to you about the details concerning getting sicker	50%
Talking about how long you may have to live (prognosis)	40%
Talking about what dying may be like	20%
Involving you in decisions about treatments if you get too sick to speak for yourself	40%
Asking about the things that are important to you	30%
Asking about your spiritual or religious beliefs	20%

Table 4

Symptoms assessed by subspecialty clinic within 6 months post diagnosis

Symptom Assessment over 6 months	by patient n=20	Clinic Visit (n = 212)			
		Oncology n = 149	Radiation n= 37	Pulmonary n = 8	Surgery n = 18
Pain	100%	95%	78%	63%	78%
Gastrointestinal	75%	44%	51%	25%	0%
Fatigue	75%	38%	46%	0%	11%
Dyspnea	80%	23%	35%	63%	44%
Anxiety	50%	15%	32%	0%	0%
Depression	35%	3%	27%	0%	0%