



Published in final edited form as:

*Ann Thorac Surg*. 2014 September ; 98(3): 955–961. doi:10.1016/j.athoracsur.2014.05.020.

## Comprehensive Long-Term Care of Lung Cancer Patients: Development of a Novel Thoracic Survivorship Program

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### Abstract

**Background**—Recent advances have improved the likelihood of long-term survival of lung cancer patients. However, little attention has been given to the growing need for dedicated survivorship care for these patients. To address this unmet need, we developed a unique follow-up care model.

**Methods**—In 2006, we convened a multidisciplinary working group to design a Thoracic Survivorship Program (TSP), which provides follow-up by a nurse practitioner (NP) trained in survivorship care. Patients with early-stage lung cancer who were disease free for at least 1 year after resection were eligible for the program, which incorporates a standardized approach to cancer surveillance. Data on symptoms and outcome were prospectively collected. Real-time electronic medical documentation was developed to optimize communication with primary physicians.

**Results**—Data were analyzed for the initial phase of the program, which comprised 655 patients. Ninety-two percent of eligible survivors who remain disease free have chosen to continue their care in the TSP, rather than receive follow-up with their thoracic surgeon. Clinically significant posttreatment symptoms were common, including fatigue (46%), anxiety (32%), chronic pain (25%), dyspnea (14%), and depression (12%). The majority of recurrences (72%) and second primary cancers (91%) in this cohort were identified by scheduled chest computed tomography at TSP visits.

**Conclusions**—Survivorship care for lung cancer patients, delivered in our NP-led TSP, is feasible, effective, and well accepted by patients. Through the implementation of a uniform, self-

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sustaining, patient-centered system, the TSP model improves upon the variation of physician-led follow-up care.

## Keywords

lung cancer; survivorship; follow-up; surveillance; recurrence

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## Introduction

There are an estimated 384,000 survivors of lung cancers, accounting for 4% of the U.S. population of adult cancer survivors [1]. Advances in screening, multimodality management, and targeted therapies will lead to even more survivors of lung cancers. Today, lung cancer can no longer be assumed to be a fatal diagnosis. More Americans yearly *survive* lung cancers than are diagnosed with leukemia, ovarian cancer, or stomach cancer [2,3]. However, little attention has been given to the unique needs of these survivors; in fact, doubts still remain over the utility of follow-up for lung cancer [4], and there is currently no standard approach to long-term follow-up.

Several factors must be considered in the development of a model for the care of lung cancer survivors. First, these individuals have a 3% to 5% risk per year of second primary lung cancers and therefore need long-term surveillance [5,6]. Second, previous reports showed that lung cancer survivors frequently report symptoms including pain, dyspnea, depression, insomnia, and fatigue [7–13]. Although some symptoms improve within a year postoperatively, impaired quality of life may persist for several years [7,10,12,14–17]. Third, preventative care, including routine screening for other malignancies, can often be overlooked in the cancer population [18]. Finally, lung cancer survivors frequently have comorbid conditions, including cardiovascular and pulmonary diseases, that require active management.

Thoracic surgeons are particularly attuned to issues of cancer surveillance in patients treated for early-stage lung cancer but may not give sufficient attention to the concerns of symptom management, quality of life, or health behavior modifications. Conversely, primary care physicians (PCPs) are not trained in the care of thoracic oncology patients. Because of the increasing number of lung cancer survivors, there is a growing need to develop standardized, comprehensive, and cost-effective models of follow-up care that address the oncologic and functional needs of these patients [19]. The urgency of this need has been underscored by the Institute of Medicine (IOM), which has made survivorship care a central recommendation for improving cancer care [20,21]. Beginning in 2015, the American College of Surgeons Commission on Cancer (ACS-CoC) now requires the provision of Survivorship Care Plans, as proposed by the IOM [20], to cancer survivors as a condition for accreditation [22].

We describe the development of a unique nurse practitioner (NP)–based long-term care model for lung and other intrathoracic cancers. To our knowledge, this is the first program developed specifically to address the comprehensive medical and psychosocial needs of lung cancer survivors and to optimize long-term care in collaboration with PCPs.

## Patients and Methods

### Memorial Sloan-Kettering Thoracic Survivorship Program (TSP) Planning Process

Guided by the IOM reports “From Cancer Patient to Cancer Survivor: Lost in Transition” [20] and “Delivering High-Quality Cancer Care: Charting a New Course for a System in Crisis,” [21] we formed a multidisciplinary working group charged with developing a care program that meets the specific posttreatment needs of patients with early-stage lung and other intrathoracic cancers. An institutional commitment to developing survivorship care allowed us to draw representatives from Thoracic Surgery, Nursing, Pulmonary Medicine, Cardiology, Psychiatry, and Thoracic Medical Oncology. Initial issues addressed included (1) eligibility criteria for the TSP, (2) type of care provider (i.e., physician versus NP), (3) patient-recruitment strategies, (4) standardized posttreatment surveillance for cancer recurrence and second primary cancers, (5) provider- and patient-reported assessment tools for identifying posttreatment psychosocial and physical needs, (6) posttreatment summary and survivorship care plan with the patient and their PCP, (7) formulation of key research questions and intervention trials, and (8) establishment of metrics by which to evaluate the impact of the follow-up clinic.

### The TSP Model of Care

The model of care was based on the proposal by Oeffinger and McCabe [23] in which an NP provides follow-up care independently in collaboration with the primary surgical and/or medical oncologist, who serves as the patient’s physician of record [24–26]. The NP is the sole provider; preapproval for the NP to bill for these visits was obtained from Centers for Medicare and Medicaid Services (CMS) and from private payors. The NP received extensive training from thoracic surgeons and medical oncologists and completed communication skills training to aid in conversations about recurrences. Ongoing supervision was then provided by one of three thoracic surgeons (V.W.R., B.J.P., or J.H.).

The target patient population was identified as patients with early-stage intrathoracic cancers who were disease free on the basis of history, physical examination, surgical findings, and computed tomography (CT) scan of the chest for at least 1 year after completion of all treatment. Patients with any intrathoracic malignancy were eligible; however, lung cancers were the predominant disease type and are the focus of this report. Eligible patients identified through a search of institutional databases received a personalized recruitment letter from their thoracic surgeon describing the TSP and encouraging participation, but not mandating it. In addition, patients were introduced to the TSP NP during follow-up appointments with their surgeon, where they could hear about the purpose and goals of the program; if agreeable, they were then scheduled to receive care in the TSP for all subsequent visits.

The follow-up visit includes the following components: surveillance for recurrence or second lung primaries; assessment and management of current and late effects; screening for second malignancies other than lung cancers; health promotion counseling for diet, exercise, and smoking cessation; referrals to cancer support groups, psychosocial counseling, and

specialists for management of comorbid conditions; and communication with the PCP [20,27,28].

### **Lung Cancer Surveillance for Recurrence and New Primary Lung Cancers**

In accordance with National Comprehensive Cancer Network guidelines, patients are seen every 6 months for the first 2 years posttreatment and undergo a history, physical examination, and contrast-enhanced CT of the chest [29] (Table 1). Patients are seen annually thereafter if they remain disease free, for a history, physical examination, and CT of the chest without contrast. The NP reviews any abnormal physical and/or radiographic findings with the physician of record, and patients are referred back to the surgical or medical oncologist for evaluation when recurrence or a new primary cancer is suspected.

### **Posttreatment Assessment Tools**

At each MSK-TSP visit, patients are asked to complete a focused health assessment form that includes a review of systems, as well as standardized questionnaires to assess pain, fatigue, dyspnea, smoking status, anxiety, and depression (Supplemental Fig 1).

### **Definitions of Recurrences and New Primary Cancers**

Local recurrence was defined as any new lesion adjacent to a staple line, to the bronchial stump, or in the residual lobe (in cases of sublobar resection). Regional recurrences involved lymph node stations 1 to 14 or the ipsilateral lung. Distant metastasis was defined as disease outside the ipsilateral hemithorax.

Second primary lung cancer was defined according to the criteria of Martini and Melamed [30]: (1) different histology from the index tumor; (2) same histology as the index tumor but diagnosed at least 2 years later; or (3) same histology as the index tumor and diagnosed within 2 years but located in a different lobe or segment, with no positive intervening lymph nodes and no evidence of metastasis.

### **Communication with Primary Caregivers**

A structured electronic progress note was developed and is completed by the NP for each encounter. To foster coordination of care, this note is automatically faxed to the patient's PCP, electronically copied to the MSK physician of record, and published to the MSK electronic medical record, which is available to all involved health professionals at MSK.

### **Treatment Summary and Care Plan**

In accordance with IOM recommendations [20], an individualized written treatment summary and care plan is provided to the patient, as well as to their PCP (Supplemental Fig 2). This document includes the dates and types of treatment received; the treating physician's and survivorship NP's contact information; the follow-up care plan, including the type of testing and frequency of visits; and recommendations for routine cancer screening and healthy-lifestyle behavior modification, including exercise, diet, and smoking cessation.

## Results

This report analyzes the initial results of the program. From January 2006 to August 2010, 655 eligible patients with lung cancer enrolled in the MSK-TSP. Patient clinical characteristics are shown in Table 2. Most patients were female (61%), and 93% were white. The majority of patients had undergone resection for stage I lung cancer as their sole treatment (78%). Acceptance of the program by patients was high, with only 8% of disease-free patients opting to withdraw from the TSP to return to their referring thoracic surgeon for their follow-up care.

In the first year, 51% of resected patients who met the eligibility criteria were successfully enrolled. The remainder either were lost to follow-up, returned to follow-up with their local physicians, failed to be flagged as eligible, or were not referred at the discretion of the treating physician. Many patients did not reside in the local area and therefore traveled from a distance; these patients returned to the care of their local physicians after their surgery.

Subsequently, the referral rate of eligible patients has ranged from 42% to 63% annually. As the program was in its initial, pilot stage, rates of TSP referral varied among MSKCC thoracic surgeons, with individual referral rates of patients ranging from 11% to 86%. As with any new initiative, there was variation across the faculty in the use of the TSP, owing to varying awareness of the program during this start-up phase of the program. Usage was entirely voluntary, and naturally the surgeons leading this effort had the highest use.

Our posttreatment assessment tool showed that physical and psychosocial sequelae were common. As shown in Tables 3 and 4, 25% of survivors experienced chronic moderate to severe pain, and 46% reported fatigue. Of the patients who completed the Baseline Dyspnea Index (BDI), 14% reported at least mild dyspnea, and an additional 23% reported functional impairment significant enough to preclude calculation of the BDI. Of the patients who completed the Hospital Anxiety and Depression Scale measure, 32% reported clinically significant levels of anxiety, and 12% had levels of depression sufficient to justify referral for psychosocial support services. Of the patients who completed the Patient Health Questionnaire (PHQ-9) assessment, 7% reported moderate to severe levels of depression. Clinically significant findings triggered referral to the appropriate consultant.

Data on baseline adherence to routine cancer screening guidelines are presented in Table 5. The majority of patients aged >50 years (75%) reported adherence to recommended colon cancer screening. Similarly, 69% of men aged >50 years had a prostate-specific antigen level checked within the previous year. For women aged >40 years, 75% had a mammography during the previous year, and 61% of all women had cervical cancer screening with a Papanicolaou smear during the previous 3 years. Patients were referred for the appropriate testing if they were found to be in noncompliance with screening guidelines.

Surveillance CT scans were performed in these patients at the intervals described earlier, and a detailed analysis of the incidence of recurrence and second primary cancers inclusive of this experience has been discussed and published separately by our group; it found that nearly all second primary cancers and the majority of recurrences were identified through

scheduled interval CT scans [6]. The majority of recurrences (72%) and second primary cancers (91%) in this cohort were identified by scheduled chest CT at TSP visits.

## Comment

To our knowledge, our TSP is the first survivorship program designed specifically for survivors of thoracic malignancies. Previously, our follow-up varied by physician and was limited solely to surveillance for recurrence or second primary lung cancers. This novel program provides standardized cancer follow-up care by a trained oncology NP, ensures screening for other cancers, successfully identifies lung cancer recurrences and new lung cancers in this high-risk population, and provides comprehensive assessment and treatment for associated medical and psychosocial issues. Our experience shows a high acceptance of this care model by patients. It validates the feasibility of an NP providing care to a group of patients who have complex health issues, within a structured program that also interfaces with the patients' PCPs. This approach is particularly important in an era when there is an increasing focus on both health care quality and costs.

The importance placed on coordinated-care systems in improving cancer care in the two IOM reports "From Cancer Patient to Cancer Survivor: Lost in Transition" and "Delivering High-Quality Cancer Care" [20, 21] illustrates the timeliness of and the need for a model of care such as our TSP. Recognizing the changing landscape of cancer demographics, the IOM draws attention to the needs of an increasingly elderly population and calls for more coordinated and comprehensive patient-centered care through team-based approaches integrating the cancer physicians with the PCP and other consultants. Central to these efforts is the systematic collection of high-quality data on patient-reported outcomes and patient characteristics, another central requirement for ACS-CoC accreditation [21, 22]. Our TSP model is very much consistent with the recommendations outlined by the IOM.

The TSP has proven financial feasibility because NPs can be reimbursed for survivorship care by CMS. This also enhances the physicians' availability to evaluate new patients rather than seeing patients for routine follow-up care. The primary benefit is decompression of the surgeon's clinic schedule, freeing him/her from follow-up visits and expanding the opportunity to see additional new patients. Furthermore, most of our surgeons have been unable to devote 45 minutes to the follow-up visits—the length of time our NPs currently spend in the performance of a comprehensive assessment. With the use of an NP-based model, the NPs are able to bill for the follow-up care (unlike residents or physician assistants) and to cover the costs of their salaries. Others have demonstrated that costs are covered by reimbursements in an NP-based survivorship model [31].

Implementation of this type of survivorship care requires a change in practice for the physician, the nursing and office staff, and the patient. Acceptance has occurred gradually. During the initiation of this program, thoracic surgeons were more likely to refer patients to the TSP when the NP worked simultaneously in their actual offices. Similarly, patients were more accepting of the referral when it was explained by the surgeon and NP together during a routine follow-up visit. Because of the success of the program, we now routinely present it to patients early in the postoperative period as standard care. As awareness and acceptance

have grown, the TSP may further evolve from an “opt-in” model to an “opt-out” model, further increasing enrollment.

We found that lung cancer survivors experience considerable physical and psychosocial sequelae, especially pain, fatigue, dyspnea, and anxiety. Our findings corroborate the published literature on this topic [12]. In these older patients who suffer from multiple comorbidities, it is difficult to determine whether symptoms are related to cancer treatment or to preexisting conditions. Nevertheless, these symptoms adversely affect survivors’ quality of life, and future efforts are aimed at developing interventions to better manage these posttreatment problems.

We recognize some limitations of our results. The patients were predominantly white with early-stage disease treated at a tertiary comprehensive cancer center. The feasibility of a thoracic survivorship program in other settings and patient populations needs to be assessed. Because the quality-of-life data presented here are derived from routine clinical assessment paper forms completed during or immediately after the clinic visit, certain elements are incomplete. We have since improved clinical informatics to ensure complete data capture and are automating our patient-report forms so that TSP enrollees can complete a self-assessment electronically before their visit. As the majority of TSP enrollees are patients with early-stage disease, one should exercise caution in generalizing our results to the larger population of lung cancer patients. However, patients with higher-stage disease who received combined modality therapy also may derive benefit from the TSP visit, with greater attention given to the management of the late effects of treatment (i.e., neuropathy, hearing loss, and cardiotoxicity). Although an effect on survival has yet to be demonstrated, proof of a survival benefit is not required to appreciate the improved quality of care that these patients receive through the TSP, compared with the heterogeneity of the surgeon-based model.

Based on our experience, we propose that patients with resected early stage lung cancers who are disease free 1 year after surgery should be considered candidates for this model of follow-up care. Posttreatment problems are frequent among survivorship patients and warrant further study. Our program has proven to be a feasible and effective model of care for lung cancer survivors and has steadily gained acceptance from physicians, nurses, and patients.

## Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

## Acknowledgments

The authors would like to acknowledge Nancy Houlihan, Richard Steingart, MD, and Marc Feinstein, MD, for their guidance in the development of the TSP clinic, and David Sewell, for his assistance and editorial support.

**Financial Support:** The Society of Memorial Sloan-Kettering Cancer Center and the LIVESTRONG Foundation.

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**Table 1**Survivorship Care Plan for Resected Lung Cancer Patients at Memorial Sloan-Kettering Cancer Center<sup>5,6</sup>

Interval	Follow-up Schedule		Primary Provider
	Visit	Testing	
Year 1	Every 6 months	Chest CT scan w/contrast	Surgeon
Year 2	Every 6 months	Chest CT scan w/contrast	Nurse Practitioner
Year 3	Annual	Chest CT scan (non-contrast)	Nurse Practitioner

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**Table 2**

## Patient Demographics (n = 655)

Characteristic	No. (%)
Age, years	
Mean (SD)	70 (9)
Range	39–91
Sex	
Male	256 (39)
Female	399 (61)
Race	
White	612 (93)
Black	22 (3)
Asian	17 (3)
Other	4 (1)
Stage	
IA	402 (61)
IB	150 (23)
IIA	15 (2)
IIB	32 (5)
IIIA	25 (4)
IIIB	21 (3)
IV	6 (1)
Missing	3 (1)
Time from first treatment, years	
Mean (SD)	3.0 (2.6)
Treatment	
Surgery alone	510 (78)
Induction therapy + surgery	71 (11)
Chemotherapy	55 (78)
Radiation therapy	2 (3)
Both	14 (20)
Surgery + adjuvant therapy	68 (10)
Chemotherapy	53 (78)
Radiation therapy	9 (13)
Both	6 (9)
Chemotherapy and/or radiation therapy alone	6 (1)
Tobacco use	
Never	93 (14)
Former	514 (78)
Current	36 (5)
No information	12 (2)

**Table 3**

## Physical Sequelae after Treatment

Variable	Symptom		
	Pain	Fatigue	Dyspnea
Subjects, no.	480	482	382
Tool/scale (possible range)	NRS (0–10)	NRS (0–10)	BDI (0–12)
Score			
Mean (SD)	2.0 (2.7)	3.4 (2.6)	10.7 (1.9)
Range	0–10	0–10	3–12
Clinical significance (score), no. (%)			
None (0)	230 (48)	86 (18)	NA
Mild (0–3)	130 (27)	172 (36)	NA
Moderate (4–7)	93 (19)	186 (38)	NA
Severe (8–10)	27 (6)	37 (8)	NA
9	NA	NA	52 (14)

Abbreviations: BDI, Baseline Dyspnea Index<sup>27</sup>; NRS, Numeric Rating Scale.<sup>28</sup>

**Table 4**

## Psychosocial Sequelae after Treatment

Variable	Symptom		
	Anxiety	Depression	Depression
Subjects, no.	250	250	239
Tool/scale (possible range)	HADS-A (0–21)	HADS-D (0–21)	PHQ-9 (0–27)
Score			
Mean (SD)	5.6 (4.0)	3.5 (3.4)	3.0 (4.3)
Range	0–19	0–19	0–27
Clinical significance, no. (%)			
8	79 (32)	31 (12)	NA
None (0–4)	NA	NA	183 (77)
Mild (5–9)	NA	NA	29 (16)
Moderate (10–14)	NA	NA	7 (3)
Moderate-severe (15–19)	NA	NA	9 (4)
Severe (20–27)	NA	NA	1 (0)

Abbreviations: HADS, Hospital Anxiety and Depression Scale<sup>29,30</sup>; PHQ-9, Patient Health Questionnaire.<sup>31</sup>

**Table 5**

## Cancer Screening

Variable	Test			
	Colorectal <sup>a</sup>	PSA	Mammogram	PAP
Population	Age >50	Men age >50	Women age >40	Women all ages
Subjects, no.	641	249	399	399
Subjects screened, no. (%)				
At any time	NA	195 (78)	360 (90)	281 (70)
Within 1 year	NA	171 (69)	301 (75)	NA
Within 3 years	NA	NA	NA	245 (61)
Within 10 years	478 (75)	NA	NA	NA

Abbreviations: PAP, Papanicolaou; PSA, prostate-specific antigen.

<sup>a</sup> Any form, including colonoscopy, sigmoidoscopy, and fecal occult blood testing.

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