



Survivor and Caregiver Expectations and Preferences Regarding Lung Cancer Treatment

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Abstract

Purpose: Treatment success in lung cancer is no longer restricted to objective measures of disease-specific outcomes and overall survival alone but now incorporates treatment morbidity and subjective quality of life (QoL). This study reports how lung cancer patients, survivors, and caregivers define treatment success and prioritize treatment decisions.

Materials and Methods: An online survey with both ranking and free-response questions was administered among lung cancer survivors and caregivers. Responses were used to evaluate treatment priorities, perceptions of treatment success based on Eastern Cooperative Oncology Group (ECOG) Performance Status, and troublesomeness of treatment-related toxicities.

Results: Among 61 respondents (29 lung cancer survivors, 28 caregivers of survivors, and 4 who were both survivors and caregivers), cancer cure was the highest priority when making treatment decisions for 74.5% of respondents, with QoL during and after treatment ranking second and third. Seventy percent of respondents felt that treatment morbidity resulting in complete dependence on others and spending the entire day confined to bed or chair would represent unsuccessful treatment. Requiring oxygen use was ranked as a very or extremely troublesome treatment toxicity by 64%, followed by shortness of breath (62%), fatigue (49%), chronic cough (34%), and appetite loss (30%). Even with remission, a 3- to 7-day hospital admission for pneumonia during treatment was deemed an unsuccessful outcome by 30%.

Conclusion: This study highlights the importance of physicians discussing in detail with their lung cancer patients their desires and goals. Accounting for factors like expected performance status following treatment, troublesomeness of treatment toxicities, and hospitalization rates may help guide treatment decisions.

Keywords: cancer survivorship; quality of life; radiation therapy; lung cancer; caregiving

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Table 1. Interview participant characteristics.

Participant	Age	Sex	Race	Diagnosis	Treatment
1	63	F	Black	Stage I, NSCLC	SBRT (x-rays)
2	79	M	Black	Stage III, NSCLC, unfavorable risk (chronic kidney disease)	Chemo/PT
3	63	M	White	Stage III, NSCLC, unfavorable risk (anemic)	Chemo/IMRT
4	75	F	White	Recurrent NSCLC, unfavorable risk (prior surgery)	Chemo/PT
5	76	F	Black	Stage IIB NSCLC, favorable	Chemo/PT
6	80	F	White	Early-stage NSCLC	SBRT (x-rays)

Abbreviations: F, female; NSCLC, non-small cell lung cancer; SBRT, stereotactic body radiation therapy; M, male; Chemo, chemotherapy; PT, proton therapy; IMRT, XXX.

Introduction

Lung cancer remains a major cause of cancer-related deaths worldwide [1]. An estimated 234 000 new cases of lung and bronchus cancer will be diagnosed in the United States this year [2]. The 5-year survival rate for non-small cell lung cancer (NSCLC), which accounts for 83% of all lung cancers [3], remains low at just 21% [4] despite new therapies. Traditionally, an increase in the 5-year survival rate has been considered an indicator of treatment efficacy. However, in recent years, how we define successful cancer care has become more complex. Clinical trials are increasingly incorporating health-related quality of life (QoL) as a primary or secondary endpoint to gain a more comprehensive picture of patient treatment and disease outcomes [6].

Cancer therapy decisions frequently require balancing the chance of cancer cure with the likelihood of treatment-induced side effects. Lung cancer survivors often suffer a high burden of both short-term and long-term side effects from treatment that can interfere with their QoL, including decreased pulmonary function (such as shortness of breath and chronic cough), difficulties swallowing (such as dysphagia and odynophagia), restricted physical ability [7], immune-mediated toxicities (such as pneumonitis and colitis) from immunotherapy drugs, and an increased incidence of other smoking-related malignancies [4].

Traditionally, objective measures like disease-specific outcomes and overall survival were implemented to determine treatment success for lung cancer. Yet, research on patient and caregivers' prioritization of cancer cure, QoL, and temporary/permanent side effects when making treatment decisions has been limited. In an effort to consider an appropriate endpoint for a study comparing proton and photon radiation for patients with locally advanced NSCLC, we sought to gain a better understanding of how patients with lung cancer and their caregivers define successful treatment, and how they make treatment-related decisions.

Materials and Methods

Survey Design

Under institutional review board approval (LUX11), a small focus group composed of survivors, caregivers, and support group attendees led by an oncologic psychologist was assembled to help facilitate the design of survey questions that capture meaningful endpoints for cancer treatment from the perspective of patients and caregivers. **Table 1** demonstrates the patient-specific, disease-specific, and treatment-specific details of these survivors.

The final survey items were written in collaboration with physicians, an oncologic psychologist, patients, survivors, caregivers, and representatives from the Lung Cancer Alliance and American Lung Association. The resulting survey was composed of demographic questions, 5 ranking questions, and 5 free-response questions to allow the respondents to elaborate on priorities involving treatment decisions and their view on what constitutes a successful treatment. To assess patients' physical functionality, patients (or caregivers) ranked treatment success on the widely used Eastern Cooperative Oncology Group, or ECOG, Performance Status (PS) scale. A Likert-type scale was used to rank side effects (such as chronic cough, shortness of breath, fatigue) from "extremely troublesome" to "not troublesome."

The survey was developed by using Survey Monkey software (**Supplemental Materials**). A link to the survey was distributed via electronic newsletters sent out by the American Lung Association in July 2015 and Lung Cancer Alliance in November 2015 to lung cancer patients, survivors, and caregivers acting as proxies for lung cancer survivors across the United States. In 2015, recipients at 41 400 email addresses received the monthly newsletter. Of these, 9.67% opened the newsletter and 0.88% clicked on one of the links. The survey was also posted to the American Lung Association Facebook page.

Table 2. Respondent demographics (N = 61).^a

Variable	No. pts (%)
Sex	
Male	6 (9.8)
Female	41 (67.2)
Prefer not to answer	14 (23.0)
Disease stage	
Stage 1	8 (13.1)
Stage 2	2 (3.3)
Stage 3	13 (21.3)
Stage 4	24 (39.3)
Limited-stage SCLC	5 (8.2)
Extensive-stage SCLC	3 (4.9)
Unknown	4 (6.6)
Prefer not to answer	2 (3.3)
Treatment	
Chemotherapy	39 (64.0)
Targeted therapy (ie, erlotinib)	15 (24.6)
Immunotherapy (ie, nivolumab)	3 (4.9)
Radiation: x-ray	26 (42.6)
Radiation: proton	8 (13.1)
Surgery	23 (37.7)
Prefer not to answer	8 (13.1)
Time since last treatment	
Still receiving treatment	17 (28.0)
<1 y ago	11 (18.0)
1–5 y ago	15 (25.0)
6–10 y ago	8 (13.1)
11+ y ago	6 (9.8)
Prefer not to answer	4 (6.6)

Abbreviations: Pts, Patients; SCLC, Small Cell Lung Cancer.

^aMedian age, 59 years (range, 28–75).

Statistics were performed by using a Microsoft Excel spreadsheet (Microsoft Corporation, Redmond, Washington) and SurveyMonkey (San Mateo, California).

Results

In total, 61 participants completed the survey, of whom 29 had a history of lung cancer, 28 were caregivers of lung cancer patients, and 4 both had a history of lung cancer and were caregivers of someone with lung cancer. The median age of initial lung cancer diagnosis was 59 years (range, 28–75 years). A vast majority of respondents identified as female (67%), white/Caucasian (93.6%), and were college graduates (70.8%). **Table 2** summarizes the demographic information of the participants. Since we found no statistical differences in ranked factors influencing treatment decisions between cancer survivors and caregivers, the groups were combined.

When questioned about lung cancer treatment decision priorities, 74.5% of respondents felt that cancer cure was the most important priority in deciding treatment. While QoL during and following treatment was ranked second and third, respectively, most respondents deemed QoL after treatment as the second most important priority in making treatment decisions (**Table 3**). Among the free-response questions, physician advice and/or expertise emerged as another important determinant in treatment decision-making, with more than a quarter of patients and caregivers citing it as an important factor when choosing cancer treatment. When asked to describe the most important considerations when choosing cancer treatment, 1 caregiver stated, “choosing his team of caregivers and surgeons” while another respondent cited “confidence in the doctor and team.” Patients were least concerned with the likelihood of temporary side effects when making treatment decisions.

Table 3. Priority of factors influencing treatment decisions.

Factors influencing treatment decisions	Highest priority:				Lowest priority:		Overall rank
	rank 1, no. pts (%)	Rank 2, no. pts (%)	Rank 3, no. pts (%)	Rank 4, no. pts (%)	rank 5, no. pts (%)		
Cancer cure	38 (74.5)	3 (5.9)	1 (2.0)	3 (5.9)	6 (11.8)	1	
Quality of life during treatment	10 (21.3)	16 (34.0)	12 (25.5)	7 (14.9)	2 (4.3)	2	
Quality of life after treatment	3 (6.5)	25 (54.4)	15 (32.6)	1 (2.2)	2 (4.4)	3	
Likelihood of permanent side effects	2 (4.0)	6 (12.0)	7 (14.0)	20 (40.0)	15 (30.0)	4	
Likelihood of temporary side effects	0 (0)	0 (0)	10 (20.8)	17 (35.4)	21 (43.8)	5	

Abbreviation: Pts, Patients.

Nearly 90% of the patients (or the caregivers' designated patient) reported being fully active and able to carry out activities without restrictions before treatment, representing an ECOG PS of 0 on a scale of 0 to 5 (with higher values indicating higher levels of disability). When presented with descriptors of ECOG scores, 74% of patients believed that a treatment was extremely or very successful even if their independence was limited to caring for themselves (eg, bathing, dressing) while remaining active for more than half the day if there was no evidence of disease after treatment (ECOG PS of 2) (**Figure 1**). The proportion of patients who deemed treatment extremely or very successful dropped to 58% if there was a recurrence of the cancer within 1 to 2 years after treatment. On the other hand, only 35% felt treatment extremely or very successful if their independence was restricted to only limited self-care and confined to a chair or bed for more than 50% of the day (ECOG PS of 3) without disease recurrence. Ninety percent of respondents felt that complete dependence on others and spending the entire day confined to a bed or chair (ECOG PS of 4) indicated an unsuccessful treatment (70%) or only a mildly successful (20%) outcome. Interestingly, 30% of patients and their caregivers deemed a 3- to 7-day hospital admission for pneumonia during treatment as an unsuccessful overall treatment outcome even if the outcome was no evidence of disease after treatment.

Additionally, patients and their caregivers were asked to assess the troublesomeness of side effects of lung cancer and treatment (**Figure 2**). Seventy-two percent of respondents felt that requiring a caretaker for assistance in bathing would be extremely or very troublesome, and 78% felt that the inability to remain active would be extremely or very troublesome. Patients qualified adverse effects, such as chronic cough, shortness of breath, loss of appetite, and fatigue, on a scale of not troublesome to extremely troublesome. Shortness of breath was ranked as very troublesome or extremely troublesome by 62% of respondents, followed by fatigue (49%), chronic cough (34%), and loss of appetite (30%).

Figure 1. Responses to questions regarding self-care that influence ECOG Performance Status. Abbreviation: ECOG, Eastern Cooperative Oncology Group.

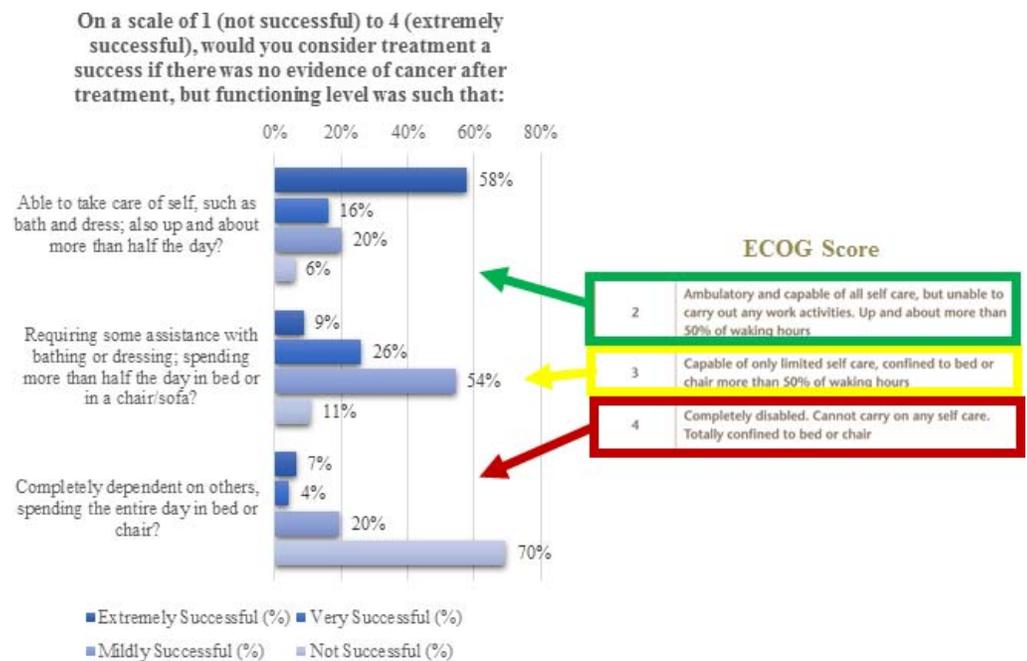
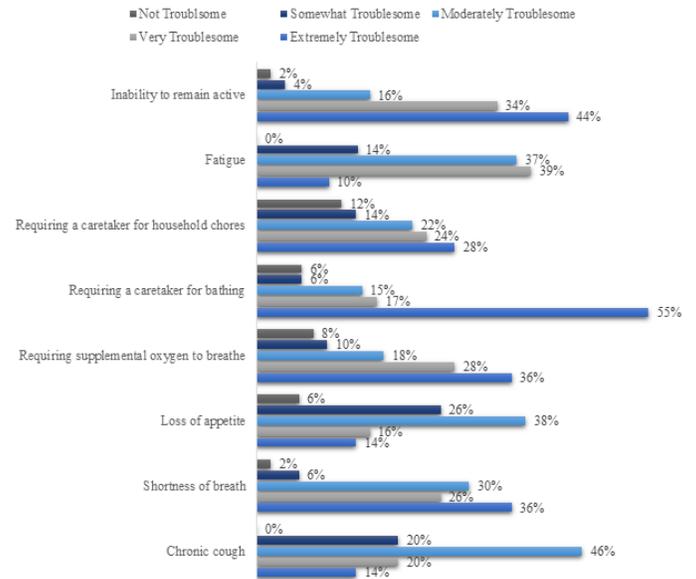


Figure 2. Responses to survey question, “How troublesome do you consider the following side effects?”

How troublesome do you consider the following side effects?



Finally, participants were asked about their feelings about participating in a clinical trial and 11.5% responded they would not participate in a clinical trial. When asked if they would participate in a clinical trial comparing proton therapy and Intensity-modulated radiation therapy (IMRT), where treatment was decided by a flip of the coin, 40% of patients reported that they would not participate. This finding could suggest that, in regard to the first part of the question, respondents may initially correlate “clinical trial” with “wonder drug.” However, when the more specific question of enrolling in a trial that offers experimental treatment or the standard treatment was asked, respondents were less enthusiastic as they might not get the experimental treatment they desired.

Discussion

Cancer treatment decision-making is rarely a simple process. Medical decisions are seldom made within dyadic relationships between physicians and patients but instead involve a broader network of families and caregivers in a process mediated by cultural nuances and personal preferences. Our study found that patients and their caregivers viewed cancer cure as the most important consideration when making a treatment decision. Unfortunately, however, prolonged disease control is not achievable for many lung cancer patients particularly those who are not candidates for targeted therapy or are not responsive to immunotherapies [8]. Nevertheless, Slevin et al [9] found that cancer patients accept intensive treatment even when the likelihood of cure or a relief of symptoms is minimal. Similarly, Weeks et al [10] analyzed metastatic lung and colon cancer patients’ life-extending treatment preferences based on an estimated 6-month prognosis. The investigators found that patients who believed they would survive at least 6 months, sometimes despite lower estimates, were more likely to prefer life-extending therapies over comfort care [10].

While cancer cure was the main determinant in selecting a cancer treatment, most respondents felt QoL after treatment was the second most important priority in making treatment decisions. Quality of life is gradually becoming a major endpoint in controlled studies, which is especially important in diseases such as NSCLC for which treatment is aggressive and can cause significant morbidity with limited improvement in patient survival. For instance, secondary analysis of the Radiation Therapy Oncology Group 0617 study, a phase III trial using a 2 × 2 factorial design to compare 60 Gy and 74 Gy with or without cetuximab in unresectable stage III NSCLC, evaluated QoL as a secondary endpoint [11]. The investigators found that after 3 months, 45% of patients in the high-dose 74-Gy arm of the trial experienced a clinically meaningful decline in QoL, as assessed via the Functional Assessment of Cancer Therapy–Trial Outcome Index, compared to 30% ($P = .02$) for patients in the 60-Gy arm, with no improvement in overall survival. While patients prioritize the chance of cure as the highest importance in selecting treatment strategies, higher radiation doses are no more efficacious and can be harmful to QoL. Additionally, secondary analysis of the AURA3 trial, a phase III trial demonstrating the use of osimertinib over platinum-pemetrexed chemotherapy in relapsed NSCLC, documented improvements in patient-reported outcomes including patients’ perspectives

of their symptoms, functional activities, and QoL as secondary outcomes [12]. The investigators found that patients had significantly improved QoL and longer time to deterioration with osimertinib than with chemotherapy for cough, chest pain, and dyspnea. As such, conversations concerning treatment strategies, while traditionally centering on cancer cure alone, should likewise emphasize QoL as a high priority in decision-making, since patients and caregivers hold QoL in high value. Patients, however, still need to understand that those who develop recurrences or experience progression while receiving less toxic and less effective therapy are likely to experience declines in functional status and QoL owing to the physical burden of the disease process or the higher toxicity of the second- and third-line therapies.

Quality of life is a subjective patient-reported treatment outcome often measured by single- or multi-item scales typically addressing emotional well-being (such as depression and anxiety), physical abilities, social interaction, and treatment toxicities (such as fatigue, pain, and cough). Our survey focused on survivorship priorities by obtaining patient-reported ranking of the troublesomeness of side effects and the importance of physical independence. Nearly 90% of the survey respondents had an ECOG PS score of 0 (fully active, no restrictions) before treatment. More than half of these patients and caregivers considered an ECOG PS of 2 (in bed <50% of the time; capability of self-care) after treatment as extremely successful, while an ECOG PS of 4 (entire day confined to bed/chair) was considered unsuccessful by nearly 70% of respondents. An ECOG score of 3 (in bed >50% of the time; capability of limited self-care) was the dividing line between high and low patient QoL outcomes (based on physical functional status) with 65% of patients deeming a PS of 3 only a mild success or not successful at all. Patient independence was an important determinant of treatment success, with more than 58% responding that treatment was extremely or very successful, even with a recurrence in 1 to 2 years, if independence was maintained. Only 11% of respondents deemed complete remission extremely or very successful if the survivor was completely dependent on others (ECOG PS of 4) after treatment. Patients' value of physical functional status is a high QoL priority that should enter into discussions when selecting treatment strategies. Studies should consider evaluating functional status following treatment, which can easily be reported through using performance status after treatment, which is commonly collected. In fact, one recent secondary analysis of RTOG 0617 data reported that among 215 2-year survivors, only 7% had an ECOG PS of 3 or 4 reported during follow-up [13].

Treatment toxicities are also of concern to survivors and their caregivers. Our data corroborate previous studies that found that loss of appetite and shortness of breath had a negative impact on patient perception of successful treatment of lung cancer [14]. Toxic side effects are often presented by frequency or duration rather than patient perception of significance [15]. Tishelman et al [15] found that lung cancer symptoms do not all carry the same importance to patients. For example, while "appearance" had a high intensity score, it was ranked the lowest in importance to lung cancer patients. Our data demonstrate that all respondents considered fatigue and chronic cough at least somewhat troublesome side effects. However, most respondents (>85%) did not feel that chronic cough, fatigue, and loss of appetite were extremely troublesome toxicities. On the other hand, shortness of breath and requisite use of oxygen were considered extremely troublesome side effects for greater than one-third of respondents, and 92% reported shortness of breath as being at least a moderately troublesome treatment side effect. Recent work has shown that side effects such as fatigue and shortness of breath may remain problematic for lung cancer patients many years into survivorship [16]. Therefore, understanding which treatment toxicities patients find most troublesome can help direct physician-patient treatment expectations and tolerances.

Surprisingly, our data showed that 30% of respondents felt that a 3- to 7-day hospital admission for pneumonia during treatment constituted an unsuccessful overall treatment outcome, despite ranking temporary side effects—such as resolved pneumonia—as the lowest priority in treatment decisions. While it is difficult to hypothesize about this finding because of the limited number of respondents, future surveys could investigate this unexpected relationship by assessing whether patients attributed the unsuccessful treatment outcome to the hospital admission (including the length of stay, discomfort, and inconvenience), the infection during treatment (its signs and symptoms, medication, and delay in treatments), or a combination of factors. While our study looked at respiratory side effects such as shortness of breath and dependence on supplementary oxygen, which were ranked extremely or very troublesome by 62% and 64% of patients, respectively, a closer assessment of patient attitudes towards pulmonary side effects is warranted.

When investigating participant interest in being involved in clinical trials few patients reported they would not participate. However, when the same people were asked about participating in a randomized trial comparing proton therapy versus IMRT, where treatment would be determined by a flip of the coin, many more patients said they would not participate. These findings are important as we find that randomized trials comparing proton versus IMRT are accruing slowly with many patients coming off study if randomly assigned to IMRT [17]. Therefore, other clinical trial strategies for conducting comparative effectiveness of

2 treatments are needed, such as the one being done in the COMPPARE clinical trial comparing proton therapy to IMRT in prostate cancer (ClinicalTrials.gov Identifier, NCT03561220)

While this survey study has provided important insights into the views of survivors and caregivers, it does have its weaknesses. Primarily, the study suffers from a low response rate and possible selection bias. When the study was first developed, it was felt that partnering with the American Lung Association and Lung Cancer Alliance would extend our reach to patients and caregivers through their email list to ensure that a large cohort with direct experience with lung cancer could be captured. While a description of and link to the survey was included in a monthly newsletter distributed via email, the denominator of living people who received the email is unknown. Patient respondents were also much more likely to be female versus male, which is somewhat unexpected considering the more common characteristics associated with lung cancer patients. Furthermore, among survey respondents, perspectives on quality of survivorship and disease control may vary from the lung cancer population who did not proactively open the survey from the newsletter or the much larger lung cancer population who did not participate in 1 of the 2 societies.

Our survey supports the collection and reporting of additional metrics for assessing the success of treatment in lung cancer patients and survivors. Factors like expected PS following treatment, reliance on supplemental oxygen, and hospitalization rates may help guide patient and caregiver treatment decisions. Physicians can use these additional metrics to re-emphasize the rarity of the side effects that patients found most concerning and help alleviate some of the fears surrounding treatment selection. Additionally, nonrandomized comparative effectiveness studies need to be explored to improve patient participation.

ADDITIONAL INFORMATION AND DECLARATIONS

Conflicts of Interest: In the past 24 months, Jennifer C. King, PhD, has served on advisory boards for AbbVie, GRAIL, Foundation Medicine, and Tesaro, and has accepted speaking honoraria from AstraZeneca and Genentech. Bradford S. Hoppe, MD, MPH, is on the scientific council for Merck & Co, Inc, and Bristol Myers Squibb. Bradford S. Hoppe, MD, MPH, is an Associate Editor of the *International Journal of Particle Therapy*. Nancy P. Mendenhall, MD, serves as Editor-in-Chief of the *International Journal of Particle Therapy*.

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Ethical Approval: All patient data have been collected under internal review board–approved protocol.

References

1. Torre LA, Bray F, Siegel RL, Ferlay J, Lortet-Tieulent J, Jemal A. Global cancer statistics, 2012. *CA Cancer J Clin*. 2015;65:87–108.
2. Tseng JF, Pisters PW, Lee JE, Wang H, Gomez HF, Sun CC, Evans DB. The learning curve in pancreatic surgery. *Surgery*. 2007;141:694–701.
3. Noone AM, Howlader N, Krapcho M, Miller D, Brest A, Yu M, Ruhl J, Tatalovich Z, Mariotto A, Lewis DR, Chen HS, Feuer EJ, Cronin KA, eds. SEER Cancer Statistics Review, 1975–2012. Bethesda, MD: National Cancer Institute. https://seer.cancer.gov/csr/1975_2015/, based on November 2017 SEER data submission, posted to the SEER Web site, April 2018. Accessed month day, year.
4. Miller KD, Siegel RL, Lin CC, Mariotto AB, Kramer JL, Rowland JH, Stein KD, Alteri R, Jemal A. Cancer treatment and survivorship statistics, 2016. *CA Cancer J Clin*. 2016;66:271–89.
5. Maruvka YE, Tang M, Michor F. On the validity of using increases in 5-year survival rates to measure success in the fight against cancer. *PLoS One*. 2014;9:e83100.
6. Bottomley A. The cancer patient and quality of life. *Oncologist*. 2002;7:120–5.
7. Yang P, Chevillat AL, Wampfler JA, Garces YI, Jatoi A, Clark MM, Cassivi SD, Midthun DE, Marks RS, Aubry MC, Okuno SH, Williams BA, Nichols FC, Trastek VF, Sugimura H, Sarna L, Allen MS, Deschamps C, Sloan JA. Quality of life and symptom burden among long-term lung cancer survivors. *J Thorac Oncol*. 2012;7:64–70.
8. Sellmann L, Fenchel K, Dempke WC. Improved overall survival following tyrosine kinase inhibitor treatment in advanced or metastatic non-small-cell lung cancer—the Holy Grail in cancer treatment? *Transl Lung Cancer Res*. 2015;4:223–7.

9. Slevin ML, Stubbs L, Plant HJ, Wilson P, Gregory WM, Armes PJ, Downer SM. Attitudes to chemotherapy: comparing views of patients with cancer with those of doctors, nurses, and general public. *BMJ*. 1990;300:1458–60.
10. Weeks JC, Cook EF, O'Day SJ, Peterson LM, Wenger N, Reding D, Harrell FE, Kussin P, Dawson NV, Connors AF Jr, Lynn J, Phillips RS. Relationship between cancer patients' predictions of prognosis and their treatment preferences. *JAMA*. 1998;279:1709–14.
11. Movsas B, Hu C, Sloan J, Bradley J, Komaki R, Masters G, Kavadi V, Narayan S, Michalski J, Johnson DW, Koprowski C, Curran WJ Jr, Garces YI, Gaur R, Wynn RB, Schallenkamp J, Gelblum DY, MacRae RM, Paulus R, Choy H. Quality of life analysis of a radiation dose-escalation study of patients with non-small-cell lung cancer: a secondary analysis of the Radiation Therapy Oncology Group 0617 Randomized Clinical Trial. *JAMA Oncol*. 2016;2:359–67.
12. Lee CK, Novello S, Ryden A, Mann H, Mok T. Patient-reported symptoms and impact of treatment with osimertinib versus chemotherapy in advanced non-small-cell lung cancer: The AURA3 Trial. *J Clin Oncol*. 2018;36:1853–60.
13. Hitchcock K, Bradley JD, Morris CG, Hu C, Paulus R, Movsas B, Hoppe BS. Quality of survivorship among patients with locally advanced NSCLC treated with chemoradiation on RTOG 0617. *Int J Radiat Oncol Biol Phys*. 2017;99:E461.
14. 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;81:288–93.
15. Tishelman C, Degner LF, Mueller B. Measuring symptom distress in patients with lung cancer: a pilot study of experienced intensity and importance of symptoms. *Cancer Nurs*. 2000;23:82–90.
16. Rigney M, King J, Ciupek A. MA07.01 no longer outliers: understanding the needs of long-term lung cancer survivors. *J Thorac Oncol*. 2018;13:S378.
17. Liao Z, Lee JJ, Komaki R, Gomez DR, O'Reilly MS, Fossella FV, Blumenschein GR Jr, Heymach JV, Vaporciyan AA, Swisher SG, Allen PK, Choi NC, DeLaney TF, Hahn SM, Cox JD, Lu CS, Mohan R. Bayesian adaptive randomization trial of passive scattering proton therapy and intensity-modulated photon radiotherapy for locally advanced non-small-cell lung cancer. *J Clin Oncol*. 2018;36:1813–22.