# Timeliness of Lung Cancer Care: Assessing the Needs and Measuring Outcomes Using Patient Interviews

Marianna B. Shershneva, MD, PhD,[1] Regina M. Vidaver, PhD,[2] Toby C. Campbell, MD, MSCI,[1] Ji-Hye Kim, MS,[1] Erica Osley, BS,[3] Kurt R. Oettel, MD[3]

*[1]University of Wisconsin School of Medicine and Public Health, Madison, Wisconsin; [2]National Lung Cancer Partnership, Madison, Wisconsin; [3]Gundersen Lutheran Medical Center, La Crosse, Wisconsin*

ABSTRACT

**Background**: Some lung cancer patients experience unnecessary delays in their care in the United States. As part of a multi-organizational continuing education initiative, we wanted to design interventions to reduce time to treatment in this clinical area. However, there was a lack of published studies that would provide sufficient needs assessment information, as well as a lack of measures and methods that would allow program planners to assess educational outcomes as related to timeliness of lung cancer care. Therefore, we conducted a study to pilot-test patient interviews as a method of documenting timeliness of care.

**Methods**: We recruited 36 patients with lung cancer. The interview collecting 11 dates pertinent to lung cancer care was piloted with 20 patients. We subsequently interviewed 16 additional patients and reviewed their charts to analyze the accuracy of patient-reported data in comparison with chart-reported data.

**Results**: For 16 patients: 1) patient-reported and chart-reported median time from the first visit to provider to the first treatment was the same—41.5 days; 2) Lin's correlation coefficient indicated almost perfect agreement ($\rho > 0.99$) for 5 dates, and poor agreement ($\rho < 0.90$) for 6 dates; 3) median time difference between patient-reported and chart-reported dates varied from 0 to 8 days. Based on all interviews, median time from the first visit to the first treatment was 50 days, ranging from 5 to 2000 days. For all 36 patients, one or more possibly avoidable delays were experienced in 24 patients (67%).

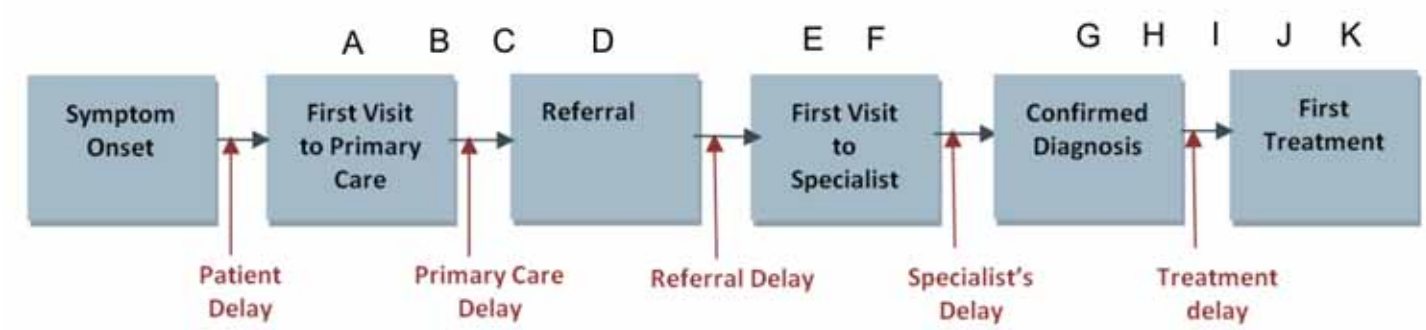
**Conclusion**: There are multiple opportunities to improve timeliness of lung cancer care. Interviewing patients has limitations, but it can be a reliable method of collecting dates regarding lung cancer care. This method can be utilized by education planners to inform the development and evaluation of educational and systems interventions to reduce time to treatment for lung cancer patients.

## INTRODUCTION

Advances in lung cancer treatment over the past decade have the potential to considerably improve the survival rate for this disease. With these advances, it is especially important for patients with lung cancer to receive timely care. Unfortunately, delays at various points in the continuum of lung cancer care have been documented in many countries [1]. Although studies in the United States are limited, data suggest practice gaps. Seven of twelve U.S.-based studies took place within the Veterans Administration (VA) Hospital system and demonstrated great variability in timeliness of care. For example, median time from first radiography to first treatment for all patients in 127 VA medical centers was 63 days, varying from 23 days to 182 days across the facilities [2]. Similarly, timeliness of care varied widely among lung cancer patients in studies focused on sub-populations of Asians [3] and native Hawaiians [4], and in 2 other studies conducted in academic centers/tertiary care facilities [5,6]. Only 1 study demonstrated that surgical lung cancer patients were diagnosed and treated in a military academic medical center without delays [7]. Some of the causes of delays have been identified, but there are many unanswered questions regarding where and why delays occur in the continuum of care [2,5,6,8]. As part of a multi-organizational continuing education initiative, we wanted to design interventions to reduce the time to treatment for patients with lung cancer; however, a lack of published studies that would provide

Correspondence: Marianna Shershneva, MD, PhD, Office of Continuing Professional Development, School of Medicine and Public Health, University of Wisconsin-Madison, 2701 International Lane, Suite 208, Madison, WI 53704; (e-mail: mbshershneva@ocpd.wisc.edu).

CE Meas. 2013;7:81-85. doi:10.1532/CEM08.12112




Lung cancer care continuum and studied dates. A indicates, first visit to health care provider with symptoms indicative of lung cancer; B, first imaging test showing lung abnormality; C, patient was informed of result of imaging; D, referral to a specialist; E, first visit to specialist; F, first diagnostic test—any lung cancer-related evaluative procedure occurring after the first imaging; G, last diagnostic test that occurred before the beginning of treatment; H, patient was informed of a confirmed diagnosis; I, first referral to treatment; J, enrollment in clinical trial; K, first treatment.

sufficient needs assessment information, as well as a lack of measures and methods that would allow program planners to assess educational outcomes as related to timeliness of lung cancer care required us to gather the necessary data ourselves.

Chart review is a common method to assess timeliness of care, but it is virtually impossible in multi-site studies and in systems that do not have integrated primary care and specialist/tertiary care. Existing U.S. tumor registries have not been used to document timeliness of care because they lack necessary data. We pilot-tested patient interviews in a search of a feasible approach to measure delays in lung cancer care across multiple health care systems. This methodology study was approved by the University of Wisconsin Health Sciences Institutional Review Board (IRB) and the Gundersen Lutheran IRB (La Crosse, Wisconsin).

## METHODS

We conducted a mixed-methods study to pilot the patient interview technique focusing on dates relative to lung cancer care and to assess the accuracy of date recall by patients. The interview approach was adopted from 2 studies where researchers utilized patient interviews in combination with either physician interview [9] or chart review [10]. Both studies showed evidence of patients being able to recall the dates of their care, although the accuracy of recall was not evaluated.

Eleven dates of interest were defined based on previous publications [9-11]. These dates pertained to the following events: A, first visit to primary care/any health care provider with symptoms indicative of lung cancer; B, first imaging test showing lung abnormality (i.e., a suspicious nodule or mass on an x-ray, CT, etc.; if repeated scans, the date of the first scan); C, patient informed of result of imaging; D, referral to specialist (e.g, pulmonologist, thoracic surgeon, oncologist, multidisciplinary lung cancer clinic); E, first visit to specialist; F, first diagnostic test after initial imaging (i.e., any lung cancer–related evaluative procedure occurring after the first imaging and before diagnosis); G, last diagnostic test; H, patient informed of a confirmed diagnosis; I, first referral to treatment (i.e., the earliest date following initial imaging on which the patient was referred for radiation therapy, chemotherapy, or a surgical treatment); J, enrollment in clinical trial (if applicable); and K, first treatment (i.e., the earliest date following diagnosis on which the patient received radiation therapy, chemotherapy, or a surgical treatment). The Figure illustrates typical positions of these dates in respect to the lung cancer care continuum and possible delays.

Patients were recruited from 2 clinical sites in Wisconsin. To increase the diversity of patients and patterns of care they have experienced, we selected sites that had different geographic locations and those with and without affiliation with an academic institution. At the first site, an urban academic oncology center, the sample included 20 patients with non–small cell lung cancer; the mean age was 63.55 years (standard deviation [SD], 8.09). At the second site, a rural community oncology center, the sample included 15 patients with non–small cell lung cancer and 1 patient with small cell lung cancer; the mean age was 60.25 years (SD, 9.40). Patients at the first site were interviewed to pilot the interview technique. Resulting interview modifications included asking a patient to tell his or her story and then going over the story to clarify the dates, and encouraging strategies to facilitate recall, such as using family calendars and medical bills.

At the second site, all patients were interviewed using the modified technique, and their charts were reviewed to extract the dates. Dates reported by patients were then compared to the dates from corresponding charts. We calculated mean differences

**Table 1. Measures of Agreement between Patient-Reported and Chart-Reported Event Dates (16 Patient Cases)**

| Dates | Number of Cases* | Lin's Correlation Coefficient, ρ (95% Confidence Interval) | Median Time Difference, days (95% Confidence Interval) |
|---|---|---|---|
| A. First visit to health care provider | 15 | 0.711 (0.345–0.890) | 7 (0–34) |
| B. First imaging test showing lung abnormality | 15 | 0.775 (0.475–0.914) | 2 (0–8) |
| C. Patient was informed of result of imaging | 15 | 0.773 (0.472–0.913) | 2 (0–8) |
| D. Referral to a specialist | 9 | 0.695 (0.177–0.912) | 8 (0–25) |
| E. First visit to specialist | 16 | 0.785 (0.492–0.918) | 6 (0–21) |
| F. First diagnostic test | 14 | 0.773 (0.455–0.916) | 4 (0–8) |
| G. Last diagnostic test | 13 | 0.995† (0.984–0.998) | 5 (0–12) |
| H. Patient was informed of a confirmed diagnosis | 12 | 0.996† (0.986–0.99) | 8 (2–13) |
| I. First referral to treatment | 13 | 0.994† (0.980–0.998) | 5 (1–11) |
| J. Enrollment in clinical trial | 4 | 0.993† (0.899–1.000) | 1 (0–26) |
| K. First treatment | 15 | 0.993† (0.899–1.000) | 0 (0–1) |

*Reflects the number of patient cases where both the date from interview and the date from medical record were available.
†Suggests almost perfect agreement [13].

between the dates from both sources. Agreement between the patient- and chart-reported dates was also assessed using Lin's concordance correlation coefficient (ρ) [12] and interpreted based on the ρ value as poor (<0.90), moderate (0.90–0.95), substantial (0.95–0.99), and almost perfect (>0.99) [13].

Additionally, we evaluated key time intervals in the full sample of 36 patients and conducted qualitative analysis of each case to identify possible reasons for delays. For this purpose, delays were defined as initial evaluation delay (AD > 60 days and/or missed opportunity to suspect lung cancer); referral delay (DE > 7 days); specialist/diagnosing delay (EI > 30 days); and specialist/treatment delay (IK > 21 days) (see definition of dates A, D, E, I, and K, and related intervals in Figure). These definitions were formulated based on recommendations that were available at the time of planning this study (i.e., British [14] and Canadian [15] guidelines) and expert input. The research team consulted with the Advisory Committee, consisting of 3 medical oncologists, 2 pulmonologists, 1 radiation oncologist, 1 surgeon, 2 primary care clinicians, 1 statistician, and 2 lung cancer survivors, to refine the study design and interpret the findings.

## RESULTS

Overall, patients could not recall 5% of the dates of interest, and 2% of the dates were not documented in the patients' charts. For the 16 patients for whom interview/chart comparison was done, patient-reported and chart-reported median time from the first visit to health care provider to the first treatment was the same—41.5 days—although the patient-reported interval ranged from 22 to 189 days and the chart-reported interval ranged from 22 to 411 days. For 5 of the dates Lin's correlation coefficient indicated almost perfect agreement, ρ > 0.99, and for 6 dates poor agreement was observed, ranging from ρ = 0.69 to ρ = 0.78. Greater agreement was observed for the dates starting with the last diagnostic test until the first treatment. The median time difference between patient-reported and chart-reported dates for the 11 dates of interest varied from 0 to 8 days (Table 1).

Based on all interviews, key time intervals varied (Table 2). The median time from the first visit to a health care provider to the first treatment (i.e., primary time interval) was 50 days, ranging from 5 to 2000 days. We observed that the distribution of time intervals in cases with shorter versus longer primary time intervals was different. When patients moved through the health care system relatively quickly, they spent more time with specialists than with primary care physicians/others who did the initial evaluation. In cases with the longest timelines, patients experienced the greatest delays at the primary care/initial evaluation stage.

Review of interview notes and recordings revealed that 1 or more possibly avoidable delays were experienced by 24 of 36 patients (67%). Reasons for delays included: 7 related to a failure to suspect lung cancer (e.g., giving a patient 3 courses of antibiotic for sinusitis), 2 related to poor provider–patient communication (e.g., a health care provider informing a patient to wait for a phone call and not calling), 4 related to lack of communication among providers (e.g., transfer of care issues), 22 systems issues (e.g., waiting for an appointment with a specialist), and 5 patient-related reasons (e.g., missing a follow-up appointment).

For example, a 68-year old male patient, whose story started with a visit to a family physician with persistent symptoms of cold, reported 2 delays. First, when a nurse called the patient with the result of the first chest x-ray and said it was possibly cancer and a follow-up appointment was needed, the patient "shut his mind," said nothing

**Table 2. Patient-Reported Key Time Intervals**

| | Interval, days* | | | | | | |
|---|---|---|---|---|---|---|---|
| | AK, Primary Interval | AD, Initial Evaluation | DE, Referral | EI, Specialist/ Diagnosing | IK, Specialist/ Treatment | FG | EK |
| Number of intervals† | 35 | 26 | 27 | 33 | 34‡ | 32 | 36 |
| Median | 50.0 | 14.0 | 5.0 | 14.0 | 14.0 | 15.0 | 27.5 |
| Minimum | 5.0 | 0.0 | 0.0 | 0.0 | 0.0 | 0.0 | 2.0 |
| Maximum | 2000.0 | 800.0 | 39.0 | 55.0 | 73.0 | 702.0 | 96.0 |

*Dates: A, First visit to health care provider with symptoms indicative of lung cancer; D, referral to a specialist; E, first visit to a specialist; F, first diagnostic test (any lung cancer–related evaluative procedure occurring after the first imaging); G, last diagnostic test that occurred before the beginning of treatment; I, first referral to treatment; K, first treatment.
†When one or both dates defining an interval were not provided by a subject, the interval for this subject was excluded from analysis.
‡One interval was excluded because referral to treatment occurred before the first visit to specialist.

to his wife, and continued with his normal life. Nobody from the clinic contacted the patient regarding the missed follow-up. Diagnosis resumed 10 months later, when the patient came to the clinic again because he felt very sick. The second delay was waiting approximately 55 days for an appointment with a pulmonologist. The total time from the first primary care visit to surgery was 381 days.

## DISCUSSION

This pilot study, conducted with a small sample of lung cancer patients in Wisconsin, demonstrated that interviewing patients can be a reliable method of collecting dates regarding the diagnosis and treatment of lung cancer. Although comparisons between patient-reported and chart-reported dates revealed minor discrepancies, the research team and a multispecialty panel of clinicians who reviewed the findings concluded that patients were able to recall most of the dates and that their recall was sufficiently accurate to justify utilization of patient interviews in planning and assessing outcomes of interventions to reduce time to treatment of lung cancer, as well as further exploration of this method in future research studies.

Limitations of the patient interview method include limited recall (i.e., missing dates, estimated dates, and incorrect dates), and inability of some patients to participate in the interview (e.g., due to deteriorated cognitive function or a hearing problem). In some cases, we found it helpful to invite a family member/caregiver to join the interview and assist the patient with date recall and/or communicate directly with the interviewer (e.g., by speakerphone). We also encouraged patients to use calendars, medical bills, notebooks, or folders they may have kept regarding their disease and any other resource that could facilitate recall. Because we used a small convenience sample recruited at a rural community oncology center, our findings regarding accuracy of patient recall of dates related to lung cancer care cannot be generalized to a broader population of patients with lung cancer.

Interviewing patients about the timeliness of their lung cancer care can be beneficial when researchers want to access diverse groups of lung cancer patients, including patients who were not seen in a cancer center, and obtain patient perspectives on timeliness of care. Furthermore, given the efficiencies in using this method, it may be employed in multi-site studies that were previously too expensive or cumbersome to complete.

Two-thirds of patients in our study experienced 1 or more delays in care that could possibly be avoided. This finding is consistent with previous research [2,5,6] indicating multiple opportunities to reduce time to lung cancer treatment.

Interviews with lung cancer patients can be helpful in developing a better understanding of the magnitude of delays and where they are most likely to occur in the diagnosis-to-treatment continuum. We are currently using the piloted method in a larger needs assessment study in 2 states with divergent lung cancer incidence rates (Wisconsin and North Carolina). Furthermore, patient-reported time intervals relative to diagnosis and treatment of lung cancer could be documented before and after an intervention to measure its impact. Thus, patient interviews can be utilized by education planners, quality improvement specialists, clinicians, and administrators to inform the development and evaluation of educational and systems interventions to reduce time-to-treatment for lung cancer patients.

## ACKNOWLEDGMENTS

The authors would like to thank Heidi Moore, PhD, for her contribution to data collection and analysis. This study was part of the multi-organizational educational initiative "Improving Access to Treatment for Lung Cancer Patients (AccessTLC)." It was funded by an educational grant from Pfizer and supported by grant 1UL1RR025011 from the Clinical and Translational Science Award (CTSA) program of the National Center for Research Resources, National Institutes of Health.

## REFERENCES


1. Olsson JK, Schultz EM, Gould MK. Timeliness of care in patients with lung cancer: a systematic review. *Thorax.* 2009;64:749-756.
2. Schultz EM, Powell AA, McMillan A, et al. Hospital characteristics associated with timeliness of care in veterans with lung cancer. *Am J Respir Crit Care Med.* 2009;179:595-600.
3. Finlay GA, Joseph B, Rodrigues CR, Griffith J, White AC. Advanced presentation of lung cancer in Asian immigrants: a case-control study. *Chest.* 2002;122:1938-1943.
4. Liu DM, Kwee SA. Demographic, treatment, and survival patterns for Native Hawaiians with lung cancer treated at a community medical center from 1995 to 2001. *Pac Health Dialog.* 2004;11:139-145.
5. Singh H, Hirani K, Kadiyala H, et al. Characteristics and predictors of missed opportunities in lung cancer diagnosis: an electronic health record-based study. *J Clin Oncol.* 2010;28:3307-3315.
6. Yorio JT, Xie Y, Yan J, Gerber DE. Lung cancer diagnostic and treatment intervals in the United States: a health care disparity? *J Thorac Oncol.* 2009;4:1322-1330.
7. Seda G, Stafford CM, Parrish JS, Praske SP, Daheshia M. Population characterization, histological evaluation, and timeliness of care of surgical nonsmall cell lung cancer patients in a military academic medical center. *Mil Med.* 2012;177:748-751.
8. Stinchcombe TE, Detterbeck FC, Lin L, Rivera MP, Socinski MA. Beliefs among physicians in the diagnostic and therapeutic approach to non-small cell lung cancer. *J Thorac Oncol.* 2007;2:819-826.
9. Bjerager M, Palshof T, Dahl R, Vedsted P, Olesen F. Delay in diagnosis of lung cancer in general practice. *Br J Gen Pract.* 2006;56:863-868.
10. Vandermeer RL, Dimitry SJ, Arnold A, Ellis PM. Delays in diagnosis and initiating treatment for patients with lung cancer. *J Clin Oncol.* 2006;24: Abstract 6102.
11. Powell AA, Schultz EM, Ordin DL, et al. Timeliness across the continuum of care in veterans with lung cancer. *J Thorac Oncol.* 2008;3:951-957.
12. Lin L. A note on the concordance correlation coefficient. Biometrics. 2000;56:324-325.
13. McBride G. A proposal for strength-of-agreement criteria for Lin's concordance correlation coefficient. NIWA Client Report: HAM2005-062. 2005.
14. BTS recommendations to respiratory physicians for organising the care of patients with lung cancer: The Lung Cancer Working Party of the British Thoracic Society Standards of Care Committee. *Thorax.* 1998;53:S1-S8.
15. Reifel JL. Lung cancer. In: Asch SM, Kerr EA, Hamilton EG, Reifel JL, McGlynn EA, eds. *Quality of Care for Oncologic Conditions and HIV: A Review of the Literature and Quality Indicators.* Santa Monica, CA: RAND Corporation; 2000:133-171.