Original Article

End-of-Life Care in Lung Cancer Patients in Ontario: Aggressiveness of Care in the Population and a Description of Hospital Admissions

Lisa Barbera, MD, MPA, FRCPC, Lawrence Paszat, MD, MSc, FRCPC, and Feng Qiu, MA, MSc
Departments of Radiation Oncology (L.B.) and Health Policy Management and Evaluation (L.P.), Sunnybrook Health Science Centre, University of Toronto; and Institute for Clinical and Evaluative Sciences (L.B., L.P., F.Q.), Toronto, Ontario, Canada

Abstract

The purpose of this study was to describe (1) the aggressiveness of care in a population of patients who die of lung cancer and (2) differences in care between a sample of lung cancer patients who died in an acute care hospital (DH) and a sample of lung cancer patients who were admitted to hospital during the last six months of life but were discharged and died elsewhere (DO). All lung cancer deaths in 2002 were identified in the provincial registry. Cases were linked to administrative sources of health care data to describe the population as a whole and the aggressiveness of the care that they received. Primary data were collected from a province-wide sample of patients' hospital charts focusing on reasons for admission, care in hospital, advanced planning, pain, and disposition. In total, 5,855 patients who died of lung cancer in 2002 were eligible for inclusion in the cohort. Rates of in-hospital death, emergency room visits, intensive care unit admissions, and chemotherapy use near the end of life were 59.5%, 32.2%, 5.5%, and 4.6%, respectively. The records of 491 patients were abstracted for this study. The DH and DO groups were similar with respect to age, gender, neighborhood income level, and extent of metastatic disease. The most common chief complaints were shortness of breath, pain, inability to cope at home, and altered level of consciousness. Compared to patients in the DO group, those in the DH group presented with pain more often (19% vs. 10%, P < 0.005) and were more likely to be admitted with progressive chest malignancy (30% vs. 21%, P < 0.05). Regardless of reason for admission, pain was commonly documented as a problem during admission: 73.5% in the DH group and 62.4% in the DO group (P < 0.05). Lung cancer patients are heavy users of acute care beds and the emergency room at the end of life. Those who do or do not die in...
hospital are similar in many respects but our results suggest those dying in hospital have more problems with pain and burden from local chest malignancy. J Pain Symptom Manage 2008;35:267–274. © 2008 U.S. Cancer Pain Relief Committee. Published by Elsevier Inc. All rights reserved.

Key Words
Lung cancer, end-of-life care, in-hospital death

Introduction

Lung cancer is the most common cause of cancer death in the United States and Canada.\(^1\)\(^2\) The majority of patients present with unresectable or advanced disease and prognosis is often grave from the outset. This population is an important group to consider in the study of end-of-life cancer care.

Population-based studies of aggressiveness of care\(^3\)\(^4\) have been performed on the cancer population as a whole. Measures of aggressiveness have been based on indicators developed for use with administrative data.\(^5\) A population-based approach using administrative data allows for evaluation of the entire population of patients and avoids many of the pitfalls associated with recruiting and following a patient population.\(^6\)

There are many studies indicating that patients prefer to die outside of the acute care setting, most often at home, or possibly in a hospice setting.\(^7\)\(^8\) Certainly, acute care beds are not the ideal place to address the needs of dying cancer patients. Acute care resources used by a cancer population with advanced illness diminish the ability of this sector to manage acute illnesses. A system that provides adequate management of palliative care patients in an alternative setting, such as home or hospice, is preferable.

In this study, we evaluate indicators of the aggressiveness of care at the end of life in lung cancer patients, using administrative data. In addition, we performed a retrospective chart review on a sample of lung cancer patients who did and did not die in hospital to compare patient characteristics and care during admission. To our knowledge, there have been no studies describing reasons for admission at the end of life in lung cancer patients and comparing the admissions in these two patient groups. Differences observed in those who die in and out of acute care may indicate priority areas for improving community care, avoiding admissions and in-hospital deaths.

Methods

Study Design

This is a population-based descriptive study of a decedent cohort of lung cancer patients using administrative sources of data, in addition to a province-wide retrospective chart review. The study was approved by the Sunnybrook and Women’s College Research Ethics Board (REB), the Ontario Cancer REB, and the local REBs of community hospitals that required separate approval.

Study Population

All patients who died of lung cancer (International Classification of Diseases 9 code-162) in 2002 were identified in the Ontario Cancer Registry (OCR). Cases were excluded if (1) the diagnosis of cancer was only made on the death certificate with no prior cancer diagnosis; (2) the insurance number was invalid during the last six months of life (this precludes linkage); (3) the patient died outside of Ontario; or (4) the patient’s age was less than 20 years.

To maximize efficiency of hospital chart abstraction, a random sample of patients was not drawn from the population as a whole. Instead, a sample of hospitals in the province was taken and patients from these hospitals were eligible for abstraction. The hospitals were selected from three categories: (1) teaching hospitals or hospitals affiliated with a regional cancer center, (2) large hospitals not affiliated with a cancer center or teaching hospital, and (3) small or rural hospitals with <100 beds. Four hospitals from each of the first two categories were randomly chosen,
with the requirement that at least one be from the northern region of the province, and six hospitals were chosen from the small/rural category. This ensured that patients from different settings were included. From these institutions, patients were randomly chosen and classified as either dying in hospital (DH) or being admitted during the last six months of life but dying outside of hospital (DO). This designation was made using administrative data (see below). The DH group is larger than the DO group because more patients died in hospital than not. We abstracted the terminal admission for patients in the DH group and the longest admission in the last six months for patients in the DO group (Fig. 1).

**Administrative Data Sources**

The OCR is a population-based cancer registry. It is approximately 95% complete when all cancer diagnoses are considered. Its method of case capture is identified elsewhere.\(^9,10\) Stage is not captured in this data set. Cases identified in the registry were linked, using encrypted provincial health card numbers, to the following data sources: (1) The Ontario Health Insurance Plan (OHIP) database contains all Medicare billing claims by physicians; (2) the Canadian Institute for Health Information (CIHI)-Discharge Abstract Database contains diagnostic and procedure codes from all inpatient and outpatient hospital admissions; and (3) The Registered Persons Database (RPDB) is a roster of all Ontario residents who are eligible for OHIP and functions as a source of demographic information, such as date of birth.

**Defining Death In Hospital**

Date of death from the OCR was compared with discharge dates from the last admission record for each patient in the CIHI. When the date of discharge and date of death matched, death was considered to occur in an acute care hospital. The remainder of patients was considered to have died outside hospital.

**Data Collection**

Administrative sources of data were used to define the following variables: (1) Age at death: we subtracted date of birth in RPDB from date of death in OCR; (2) Gender: as
per OCR; (3) Histology: as per OCR; (4) Income Quintile: we linked data from the 2001 Canadian Census with postal code from RPDB using a postal code conversion file to construct community income quintiles; (5) Comorbidity: We used diagnoses coded in CIHI-Discharge Abstract Database in the last six months of life to calculate the Deyo modification of the Charlson score, with the scores for primary and metastatic cancer subtracted.

Indicators of the aggressiveness of care were identified using OHIP claims. These claims identified care delivered in the emergency room (ER), the intensive care unit (ICU), and the administration of intravenous chemotherapy.

Primary data were collected from retrospective review of hospital charts for the DO and DH groups. Four data abstractors (a health records administrator and three registered nurses) with previous chart abstraction experience abstracted the data. All chart data were directly entered into a Microsoft Access database. Data were cleaned and numerous logic checks were used prior to analysis. The primary data collected focused on reasons for admission, types of care providers in hospital, advanced planning, pain, and disposition.

Statistical Analysis

The study is descriptive. Proportions are presented with their 95% confidence intervals (CI) following in brackets.

Results

In total, 5,855 patients who died of lung cancer in 2002 were identified through the OCR and eligible for inclusion in the cohort. Twenty patients were excluded (19 were diagnosed with death certificate only and one had an ineligible health insurance number). The characteristics of the patients in the entire lung cancer population and the cases sampled for abstraction are presented in Table 1. The DH and DO groups were similar with respect to age, gender, neighborhood income level, and extent of metastatic disease.

Aggressiveness of Care in the Population

Results are presented in Table 2. We found that 59.5% of the lung cancer population died in an acute care bed, 32.2% had at least one ER visit during the last two weeks of life, 5.5% had an admission to the ICU, and 4.6% received at least one injection of chemotherapy during the last two weeks of life.

Results from Chart Abstraction

These results are summarized in Table 3.

Arrival at Hospital. The most common method of coming to hospital was in an ambulance from home. This was more frequent in the DH than the DO group (54.7% vs. 31.2%, \( P < 0.001 \)). Transfers from other institutions and planned elective admissions were significantly more frequent in the DO group (15.2% vs. 6.0% \( [P < 0.005] \) and 9.6% vs. 5.0% \( [P < 0.001] \).
1.8% \( [P<0.001] \), respectively). Transfers from local clinics and arrival from home by car were similar in both groups at approximately 10% and 21% each.

**Reasons for Admission to Hospital.** The most common chief complaint in both the DH and DO group was shortness of breath. Other common chief complaints included pain, inability to cope at home (i.e., no acute medical diagnosis), and altered level of consciousness. Only pain was significantly different in the DH and DO groups (19.0% [95% CI 14.8%–23.2%] vs. 9.6% [95% CI 5.0%–14.2%]). The most common admitting diagnosis in both groups was progressive chest disease. This was significantly higher in the DH group (29.6%) than the DO group (20.8% \( [P<0.005] \)). The other top admitting diagnoses are listed in Table 3. We estimate that 7% of the DH admissions and 13% of the DO admissions may have been for reasons not primarily related to lung cancer, for example, stroke or myocardial infarction.

Admission for treatment-related toxicity occurred in 5.9% (95% CI 3.4%–8.5%) of DH and 10.2% (95% CI 5.5%–14.9%) of DO patients. The most common treatment-related toxicity was febrile neutropenia at 2.4% (95% CI 0.8%–4.0%) of DH patients and 4.5% (95% CI 1.2%–7.7%) of DO patients.

At the time of admission, approximately 50% of all patients had documented metastatic disease. There was no difference between the DH and DO groups with respect to sites of metastatic disease: 19% had brain metastases, 21% had bone, 15% had liver, 14% had other.

**Services and Treatment in Hospital.** There was no significant difference between the...
proportions of patients receiving chemotherapy or radiation therapy while in hospital, although anticancer treatment occurred more commonly in the DO group. Four percent of DH and 6% of DO patients received chemotherapy during their admission. The most common reasons for admission in these patients were progressive chest malignancy, pneumonia, and liver metastases. Eight percent of DH and 15% of DO patients received radiation during their admission. The most common reasons for admission for these patients were progressive chest malignancy, pain, brain metastases, spinal cord compression, bronchial obstruction, and superior vena cava obstruction.

ICU admission occurred in 10% of the DH group and 8% in the DO group. The most common reasons for admission to the ICU were respiratory failure and arrhythmia. Twenty-three of the 34 DH patients admitted to ICU actually died in the ICU (68%).

The median length of stay for a terminal admission was 10 days. In the DH group, 45% of patients had blood work drawn within 48 hours of their death.

A social work visit was documented in the charts of 22.6% (95% CI 18.1%–27.1%) of DH patients and 26.7% (95% CI 19.8%–33.7%) of DO patients. Eleven percent (95% CI 7.7%–14.4%) of DH patients and 12.1% (95% CI 7.0%–17.2%) had a pastoral care visit documented in their chart. Values presented reflect what was documented in the chart.

Family medicine was the most common admitting service, followed by general medicine, palliative care, and hospitalist programs. There were no statistically significant differences between the DH and DO groups with respect to admitting service. The actual values are not presented because they may not be generalizable to the entire population. Different institutions have different services (e.g., not all hospitals have acute care palliative care beds).

Pain. Although fewer than 10% of patients had pain documented as a reason for admission, the majority had pain documented as a problem during the admission: 73.5% in the DH group, 62.4% in the DO group (P < 0.05). Of those with pain, 98.3% in the DH group and 92.9% in the DO group had opioids ordered. Approximately half of patients in both groups had a coanalgesic ordered with the opioid.

Advance Directives and Resuscitation. “Do Not Resuscitate” (DNR) orders were much more frequent in the DH group (89.5%) than the DO group (55.4% [P < 0.001]). The most common form of advance directive was a written note in the patient’s chart. Only a few percent of patients had a formal living will document filed on their chart. The difference in advance directives (formal or informal) was slightly higher in the DH group, 31.8% (95% CI 26.9%–36.8%) vs. 21.0% (95% CI 14.6%–27.3%) in the DO group. Approximately 90% of patients with advance directives had a DNR order. About one-third of patients with a DNR order had advance directives.

The majority of DNR orders were not accompanied by any additional documentation. In all, 4.2% of the DH patients were resuscitated prior to their death. The median time between the date of DNR and death was five days in the DH group. The median time between date of DNR and discharge date was 10 days in the DO group.

Disposition. Approximately 50% of the DO patients were sent home. Of patients who died in hospital, 14% were awaiting transfer to another institution.

Discussion
The indicators of aggressive care in the lung cancer population indicated that a significant proportion die in hospital and visit the ER in the last two weeks of life. These values are greater than those reported for the general cancer population in Ontario. Rates of ICU admissions and chemotherapy injection during the last two weeks are similar to the general cancer population. These observations confirm that lung cancer patients at the end of life are heavy users of the acute health care system.

The population-based chart review comparing lung cancer patients who do or do not die in hospital reveals these two groups to be surprisingly similar. The exceptions are the frequency of active local disease and pain. Clearly, for both groups, improved management of
dyspnea and pain in the community and ambulatory care setting would be required to prevent hospital admission.

Although a small proportion of patients were receiving aggressive anticancer treatment prior to death, it is not obvious from this study that patients are being overtreated prior to death. However, almost half of patients had blood work drawn within two days of death, which suggests there were still active medical interventions underway. The rates of DNR in the DH group are similar to those reported in other similar studies. The orders were typically written about halfway through the admission in this group.

The proportion of patients dying in acute care hospitals in this study compares favorably with other provinces in Canada, where rates are reported to be 70% or higher, but are higher than the 30% reported in the United States. In Nova Scotia, 57% of patients were reported to have at least one visit to the ER during the last six months of life. For Quebec breast cancer patients, this rate is 42%. In the United States, approximately 9% had more than one ER visit during the last month of life. Because of definition differences, these rates are not all directly comparable, but Ontario’s rate of 32% during the last two weeks appears high by comparison. The rate of admission to ICU compares more favorably and may be less cause for concern. In the United States, the rate is reported at 10% during the last month, and in Ontario, the rate is 6% during the last two weeks. Chemotherapy use rates are not directly comparable. In the United States, 18% of those previously receiving chemotherapy receive chemotherapy during the last two weeks. In Quebec, 38% of breast cancer patients received chemotherapy during the last six months.

These observations are important for two reasons. First, it is of utmost importance to patients that their symptoms be controlled. Clearly, regardless of whether or not death occurs in hospital, the majority of patients in this study were admitted for symptom control issues. This suggests poor symptom control in the community. Second, many studies indicate that most patients would prefer to not die in the acute care setting. In Ontario, the majority of cancer patients die in acute care hospitals. Unless their symptoms can be adequately controlled in alternative settings, it will be difficult to shift the location of death.

The strengths of this study include the population-based sample and the acquisition of patients and hospitals from all over the province, not just a single institution or a sample of only larger teaching hospitals. The comparison of patients who do and do not die in hospital is novel. Limitations include the difficulty in collecting some data in a retrospective fashion. For example, drug doses or the degree of symptom control obtained during admission were not often abstracted, which made it difficult to assess pain and symptom severity. We did not attempt to collect information about the patients’ home support system (e.g., live alone) or information about initial stage or management. Finally, as is the case with any study relying on administrative health care data, one must remember that the data sources used were not collected for health research purposes, but rather for administration of the health care system.

Ideally, cancer patients would have their symptoms managed outside of the acute care setting (e.g., at home or in hospice) and would avoid admission to hospital. Acute care beds are not usually the best place to address the needs of palliative care cancer patients. The observations in this study would suggest that other important acute care resources are also being used to support this patient population. For example, the majority of admissions arrived by ambulance to the emergency department. Further, approximately 10%–15% of the admissions were primarily for “not coping,” which presumably could have been avoided with better support in the community, not necessarily related to specific symptom control. Also, 15% of the patients who died in hospital were waiting for a transfer to another institution, likely a palliative care unit. It is possible that this number underrepresents the number of patients who could have been transferred because palliative care units are nonexistent in many communities.

For those who actively manage lung cancer, the results of this study suggest that methods to improve local control with better treatment at diagnosis will likely improve symptoms and need for admission down the road, that is, local control is an important endpoint for evaluating new treatment, not just survival. For
those who provide supportive care, improvements are needed in the management of shortness of breath and pain in the community. For those who are involved in structuring the health care system, structures and process must be in place to support patients in the community with significant symptom distress to minimize interactions with the acute care sector.

References


