Resource use in the last three months of life by lung cancer patients in southern Ontario

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ABSTRACT

Background  End-of-life cancer care involves multidisciplinary teams working in various settings. Evaluating the quality of care and the feedback from such processes is an important aspect of health care quality improvement. Our retrospective cohort study reviewed health care use by lung cancer patients at end of life, their reasons for visiting the emergency department (ED), and feedback from regional health care professionals.

Methods  We assessed 162 Ontario patients with small-cell and relapsed or advanced non-small-cell lung cancer. Demographics, disease characteristics, and resource use were collected, and the consenting caregivers for patients with ED visits were interviewed. Study results were disseminated, and feedback about barriers to care was sought.

Results  Median patient age was 69 years; 73% of the group had non-small-cell lung cancer; and 39% and 69% had received chemotherapy and radiation therapy respectively. Median overall survival was 5.6 months. In the last 3 months of life, 93% of the study patients had visited an oncologist, 67% had telephoned their oncology team, 86% had received homecare, and 73% had visited the ED. Death occurred for 55% of the patients in hospital; 23%, at home; and 22%, in hospice. Goals of care had been documented for 68% of the patients. Homecare for longer than 3 months was associated with fewer ED visits (80.3% vs. 62.1%, \( p = 0.022 \)). Key themes from stakeholders included the need for more resources and for effective communication between care teams.

Conclusions  Use of acute-care services and rates of death in an acute-care facility are both high for lung cancer patients approaching end of life. In our study, interprofessional and patient–provider communication, earlier connection to homecare services, and improved access to community care were highlighted as having the potential to lower the need for acute-care resources.

Key Words  Lung cancer, NSCLC, SCLC, resource use, end of life

INTRODUCTION

Evaluation of the quality of cancer care is an important aspect of health care delivery. It is important that health care outcomes reflect not only process measures, but also patient-oriented outcomes. With respect to the quality of end-of-life care, various measures—including use of chemotherapy in the last 2 weeks of life, use of acute-care resources such as the emergency department (ED) and admission to hospital, and frequency of documentation of advance directives—have all been proposed as measures of patient-oriented end-of-life care quality.\(^1-6\). Prior research in Ontario has demonstrated that, in a significant proportion of cancer cases, measures of aggressive end-of-life care are evident. Ho et al.\(^1\) reported that 22.4% of Ontario patients with cancer who died between 1993 and 2004 received chemotherapy in the last 2 weeks of life, had made than 1 visit to the ED or were hospitalized within 30 days of death, or had been admitted to the intensive care unit at least once within 30 days of death. Although that percentage differs by country, multiple published studies, including those conducted in the United States, continue to demonstrate aggressive care leading up to end of life, and reducing the use of those interventions
is felt to be an indicator for improvement in the quality of end-of-life care. 

Available data suggest that most patients prefer to die at home. Mounting evidence is documenting improved psychosocial well-being for patients and less emotional distress for caregivers when patients die at home or in hospice rather than in hospital. Increased use of community-care resources is reported to reduce the use of acute-care services and to lower the proportion of patients dying in hospital. Analysis of population-based data from Ontario supports these findings. Patients admitted to home care more than 4 weeks before death were significantly less likely to visit the ED, to be admitted to the hospital, or to die in hospital. In addition, involvement of home care services, including in-home palliative care provision, has been associated with increased satisfaction with care and lower costs to the health care system. Increased hours of nursing visits per week was also associated with reduced use of acute-care services.

However, despite patient preference and better health care outcome measures, most cancer deaths still occur in hospital, and use of acute-care health services remains high for patients approaching end of life. Analysis of administrative databases for 2003–2005 demonstrated that 76,759 of 91,561 patients (83.8%) dying from cancer visited the ED during their last 6 months of life, and 31,076 (33.9%) visited the ED in the final 2 weeks of life. The most common reasons for visiting the ED were abdominal pain, lung cancer, pneumonia, dyspnea, and fatigue or malaise.

Lung cancer is both the leading cause of cancer death in North America and one of the leading causes of visits to the ED for patients near the end of life. Those visits represent a substantial health issue, because multiple published studies have demonstrated that ED visits by patients nearing end of life is a sign of aggressive care that can lead to decreased quality of life.

Understanding the end-of-life health needs of lung cancer patients therefore has significant clinical and resource allocation implications. The extent to which those visits and hospitalizations are avoidable is unclear. To try to better understand the appropriate balance between acute care and community-based care for this group of patients, we therefore attempted to understand regional resource use by lung cancer patients at end of life. We hypothesized that a high proportion of lung cancer patients would visit the ED in the last 3 months of life and that earlier integration of community palliative care might help to alleviate the need for aggressive end-of-life care. As a second portion of the study, we planned a dissemination strategy to communicate the results and obtain feedback from acute-care and community-care health care professionals.

**METHODS**

In this retrospective cohort study, institutional medical records, information from family doctors, and Community Care Access Centre (CCAC) records for patients were reviewed. Also, where possible, caregivers were interviewed to evaluate resource use by lung cancer patients during their last 3 months of life. The cohort included all consecutive patients with newly diagnosed stage III or IV non-small-cell lung cancer (NSCLC), with stage I or II NSCLC experiencing documented relapse, and with small-cell lung cancer who had been referred to 1 regional and 1 community cancer centre during a 6-month period and who were known to be deceased by the end of the 2-year study period.

Patients were identified from a search of ons, the regional electronic medical record database, and eligibility was confirmed by chart review. Patients were seen at either the Juravinski Cancer Centre (Hamilton) or the Walker Family Cancer Centre (St. Catherines) in Ontario. Patients who were seen at the Juravinski Cancer Centre only for consideration of radiation, but whose treatment was coordinated at another centre, were not included unless they were eligible for inclusion in the Walker Family Cancer Centre cohort. Patients who had their initial consultation within the 6-month period of interest and who died within 24 months after the start of the study were included. Patients were considered to be living at the end of the study period if they had been seen within the last 3 months of the study period and were scheduled to return to the cancer centre. For patients not seen in the last 3 months, and whose status was unknown, electronic searches of hospital records and local newspaper obituaries were conducted. If a patient’s status was still unknown, a fax was sent to the family doctor requesting the patient’s vital status, including date of death, if known. The study population consisted of patients known to be deceased by the end of the study period.

The information collected was age and sex; marital status and number of people living at home (if recorded); date of lung cancer diagnosis and date of death; diagnosis, stage, and treatment information; number of visits to the cancer centre; family doctor; ED visits and hospitalizations; and referral to CCAC and palliative care services. Because of missing data and an inability to reliably assess the number of people living at home, that variable was eventually dropped. Information was also collected about the number of telephone calls to the cancer centre and documentation of end-of-life directives. A letter was sent to the caregivers of patients known to have visited the ED during their last 3 months of life. The letter was sent on behalf of the most responsible treating physician and invited the caregiver to take part in a telephone interview about the ED visit. Interested individuals were asked to call the research team to schedule a semi-structured interview exploring the reasons for the ED visit. Caregivers were asked questions about the nature of the problem resulting in the ED visit; about who, if anyone, was called before the visit to the ED; whether an attempt was made to obtain help from the CCAC before going to the ED; and the outcome of the ED visit.

Data were analyzed using the IBM SPSS Statistics software application (version 19.0: IBM, Armonk, NY, U.S.A.). The primary outcome was the proportion of patients visiting the ED in the last 3 months of life. Secondary outcomes included the proportion of patients receiving chemotherapy within the last 14 days of life, the frequency of palliative care referrals, use of CCAC services, number of telephone calls to the cancer centre, number of hospitalizations, and place of death. Institutional ethics approval was obtained from the Hamilton Health Sciences and Niagara Health System research ethics boards. This project was supported...
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The final component to this research was a planned strategy of results dissemination to acute-care and community-care health care providers. A regional meeting of oncologists, nurses, and CCAC and palliative care teams, plus representatives from family medicine and the ED, was held. The objectives of the meeting were to disseminate results of the present research, to discuss strengths and weaknesses, and to consider implementation strategies to increase the use of community resources in lung cancer patients approaching end of life.

RESULTS

Of 323 patients seen for a diagnosis of lung cancer during the study period, 162 patients were included in the final study cohort. Reasons for ineligibility included stage I or II NSCLC without a documented relapse (n = 59), patient still alive at the end of the study period (n = 55), initial consultation outside the study period (n = 21), patient care transferred to or from another institution (n = 23), and diagnosis other than lung cancer (n = 3). Table 1 summarizes the baseline demographics for the cohort.

The 162 patients (53% men, 73% with NSCLC histology) included in the study had a median age at diagnosis of 69 years. During the course of their illness, 39% and 69% received systemic therapy and radiation therapy respectively, with most of them (n = 75) receiving treatment in the last 3 months of life (Table 1). Median overall survival in this cohort was 5.6 months (Table 1).

Acute-Care and Outpatient Resource Use in the Last Three Months of Life

In their last 3 months of life, 93% of patients were seen by a cancer specialist for a median of 2 ± 1.9 visits (standard deviation). Although considerable variability was evident, a median of 1 ± 2.9 telephone calls per patient were received from the 67% of patients who engaged in telephone conversations with their cancer care team within the same period.

Most patients (n = 118, 73%) visited the ED during their last 3 months of life, and 34% made multiple visits to the ED (supplementary Figure 1). Most visits to the ED by the 105 patients with available visit times were made during daytime hours (8h00–17h00, n = 61, 58%); 27 visits (26%) were made between 17h00 and 00h00, and 17 (16%) were made between 00h00 and 8h00. The most common reason for presenting to the ED was shortness of breath or pneumonia, followed by pain-related problems, neurologic symptoms, and general decline in health status (Table II). Of the patients who visited the ED, 29 were admitted to hospital, 7 of whom died in the ED (Table II).

Six patients were hospitalized on more than one occasion from the ED. Hospitalization directly from the cancer centre occurred in 36 patients (22%). Common reasons for hospitalization from the cancer centre included respiratory issues or shortness of breath (36%), general decline (14%), pain (11%), and neurologic complaints (11%). Multiple admissions from the cancer centre occurred in 6 of the 36 patients (17%).

Fourteen caregivers of patients who visited the ED, accounting for 26 ED visits, consented to telephone interviews.

| Table 1: Patient demographics and clinical outcomes |
|------------------------|------------------------|------------------------|
| Variable               | JCC (n=75)             | WFCC (n=38)            | Overall (n=112)          |
| Patients (n)           | 124                    | 38                     | 162                     |
| Mean age (years)       | 70.2±11                | 67.3±11                | 68.9±10.8               |
| Sex [n (%)]            |                        |                        |                         |
| Men                    | 66 (53)                | 20 (53)                | 86 (53)                 |
| Women                  | 58 (47)                | 18 (47)                | 76 (47)                 |
| Marital status [n (%)] |                        |                        |                         |
| Single                 | 3 (2)                  | 1 (3)                  | 4 (3)                   |
| Married                | 84 (68)                | 23 (61)                | 107 (67)                |
| Divorced               | 8 (7)                  | 3 (8)                  | 11 (7)                  |
| Widowed                | 16 (13)                | 11 (29)                | 27 (17)                 |
| Unknown                | 12 (10)                | 12 (7)                 |                         |
| Diagnosis [n (%)]      |                        |                        |                         |
| Pathologic             | 117 (94)               | 32 (84)                | 149 (92)                |
| Clinical               | 7 (6)                  | 6 (16)                 | 13 (8)                  |
| Type of lung cancer [n (%)] |                      |                        |                         |
| NSCLC                  | 94 (76)                | 24 (63)                | 118 (73)                |
| SCLC                   | 24 (19)                | 8 (21)                 | 32 (20)                 |
| No pathology           | 6 (5)                  | 6 (16)                 | 12 (7)                  |
| Stage at initial diagnosis [n (%)] |                  |                        |                         |
| I                      | 2 (1.5)                | 1 (3)                  | 3 (2)                   |
| II                     | —                      | —                      | —                       |
| III                    | 24 (19)                | 3 (8)                  | 27 (17)                 |
| IV                     | 74 (60)                | 25 (68)                | 99 (61)                 |
| Limited-stage SCLC     | 6 (5)                  | —                      | 6 (4)                   |
| Extensive-stage SCLC   | 18 (14)                | 8 (21)                 | 26 (16)                 |
| Patient considered for curative Tx? [n (%)] |                  |                        |                         |
| Yes                    | 18 (15)                | 1 (3)                  | 19 (12)                 |
| No                     | 104 (84)               | 37 (97)                | 141 (87)                |
| Unknown                | 2 (2)                  | —                      | 2 (1)                   |
| Surgery [n (%)]        |                        |                        |                         |
| Yes                    | 1 (1)                  | —                      | 1 (0.5)                 |
| No                     | 123 (99)               | 38 (100)               | 161 (99.5)              |
| Chemotherapy [n (%)]   |                        |                        |                         |
| First-line             | 40 (32)                | 23 (61)                | 63 (39)                 |
| Second-line            | 11 (9)                 | 8 (21)                 | 19 (12)                 |
| Third-line             | 4 (3)                  | 3 (8)                  | 7 (4)                   |
| Radiation [n (%)]      |                        |                        |                         |
| Curative               | 11 (9)                 | 0 (0)                  | 11 (7)                  |
| Palliative             | 75 (61)                | 25 (66)                | 100 (62)                |
| None                   | 38 (30)                | 13 (34)                | 51 (31)                 |
| Mean overall survival (months) | 3.5±4.3              | 6.9±4.5                | 5.6±5.1                 |

JCC = Juravinski Cancer Centre; WFCC = Walker Family Cancer Centre; NSCLC = non-small-cell lung cancer; SCLC = small-cell lung cancer; Tx = treatment.
TABLE II  Reasons for first presentation to the emergency department (ED) during the last three months of life

| Reason                                  | Patient group | Overall (n=118) | Hospitalized or died in ED (n=29) |
|-----------------------------------------|---------------|----------------|----------------------------------|
| Shortness of breath or pneumonia        |               | 43 (36.4)      | 9 (21)                           |
| Pain                                    |               | 19 (16.1)      | 4 (21)                           |
| Neurologic symptoms                     |               | 13 (11)        | 3 (23)                           |
| General decline                         |               | 7 (5.9)        | 0                                |
| Abdominal pain                          |               | 6 (5.1)        | 1 (17)                           |
| Fever or infection<sup>a</sup>          |               | 4 (3.4)        | 1 (25)                           |
| Cardiac complaints                      |               | 4 (3.4)        | 3 (75)                           |
| Electrolyte abnormalities or dehydration|               | 4 (3.4)        | 3 (75)                           |
| Generally unwell                        |               | 4 (3.4)        | 0                                |
| Nausea or vomiting                      |               | 2 (1.7)        | 1 (50)                           |
| Fracture                                |               | 2 (1.7)        | 1 (50)                           |
| Constipation                            |               | 1 (0.8)        | 0                                |
| Other                                   |               | 8 (6.8)        | 3 (37)                           |
| Non-cancer issue                        |               | 1 (0.8)        | 0                                |

<sup>a</sup> Non-respiratory source.

Only 4 telephone calls were made either to the cancer centre or to the general practitioner’s office before the ED visit. Responding caregivers felt that the problem was sorted out in the ED during 22 of the 26 visits (85%), and patient admission was required in 17 of the visits (65%). Satisfaction with the ED visit was high (88%).

**Indicators of Quality End-of-Life Care**

For the 146 patients with a recorded place of death, death occurred for 81 patients (55%) in an acute-care hospital; for 33 (23%), at home; and for 32 (22%), in hospice. Eleven patients (6.8%) received chemotherapy within 14 days of death. The medical record contained documentation of a change from active treatment to supportive management in only 40% of patients. A discussion about end-of-life care was documented in 67% of patient records. Of 106 patients with a documented detailed end-of-life discussion, 91% (n = 97) indicated that their preferred goal of care was “allow natural death.”

**Use of Community Resources in the Last Three Months of Life**

Most patients were enrolled for ccac services (n = 132, 81.5%, Table III), and most of those patients were managed by palliative care teams (n = 113, 86%). Most patients received nursing services (90%). Many were receiving help from personal support workers (55%) and underwent occupational therapy assessment (59%). Physiotherapy, speech therapy, and nutrition were uncommon services provided in the community.

Patients who were enrolled for ccac services appeared less likely to present to the ED (88% vs. 79%). In an exploratory analysis, we examined the length of time enrolled for ccac services and the risk of presenting to the ED. The median time in the program was 11 weeks. Patients who were enrolled for ccac services for less than 3 months (n = 71) were more likely to visit the ED in their last 3 months of life (80.3% vs. 62.1%, p = 0.022). Of the patients enrolled in ccac services, one third had been referred subsequent to visiting the ED. No difference was evident between patients who did and did not visit the ED in the last 3 months of life with respect to the median number of nursing visits per week (1.4 vs. 1.6) or the median number of personal support worker hours provided per week (1.0 vs. 1.3).

**Dissemination of Results to Health Care Providers**

A few key themes about barriers to delivery of community-based care emerged from the stakeholder meetings. It was felt that effective exchange of information between acute care and community providers was lacking, such that electronic charts of a patient’s progress in hospital were often not available to the ccac. A mismatch between supply and demand in community ccac and palliative care resources meant that there were not enough palliative care health practitioners to meet the needs of palliative patients at home. The various hospitals showed regional variability, such that the availability of hospice beds and end-of-life care differed depending on the patient’s home address. Finally, there was a discrepancy between the knowledge and skillset needed and those available from community nursing providers, given the high turnover rate in such jobs partially because of low remuneration and, sometimes, low job satisfaction.
DISCUSSION

In this retrospective cohort study, we confirmed that the use of acute-care resources toward the end of life remains high in lung cancer patients; 74% of our study population visited an ED at least once during the last 3 months of life. Our findings are similar to those from earlier studies that reported high rates of ED visits toward the end of life for lung cancer patients. Temel et al. reported similar results in a small prospective study in which 48% of 46 patients had visited the ED in the last month of life. Earlier studies also identified lung cancer as a leading cause of hospitalization and ED visits in all cancer patients. Those findings present opportunities for improvement in the quality of end-of-life care.

Prior studies have found links between early implementation of palliative care and reduced frequency of aggressive end-of-life care, including ED visits. In our study, although there was high use of community palliative care resources, most of the patients were referred to those resources within their last 3 months of life, resulting in less time for effective implementation of services. That late referral is seemingly reflected in the more frequent ED visits made by patients enrolled in the community-care programs for less than 3 months, as was also observed in prior studies. Our findings support the need for early implementation and integration of palliative care services into the care of patients with advanced cancer, which helps to improve both patient quality of life and caregiver satisfaction. In addition, compared with other patients, those who receive earlier palliative care do not incur more expenses within the system.

Prior studies have drawn a low response rate, and thus the true determination of satisfaction with ED visits and end-of-life care might be at risk of selection bias. Finally, because of limitations in data collection and sample size, our study did not include a more in-depth comparative analysis of levels of palliative care access in community and academic centres, nor did it include other composite scores of aggressive end-of-life care measures such as admission to the intensive care unit.

Our data demonstrate that patients with lung cancer are frequently hospitalized toward the end of life. In our series, 19% of patients were admitted to hospital through the ED in their last 3 months of life, and an additional 22% were admitted to hospital directly from the cancer centre. Common reasons for presenting to the ED—such as shortness of breath, pain, and neurologic problems—appear to be beyond the scope of care for many of the homecare resources. In feedback from health care providers, that shortfall was clearly identified as a barrier to effective community-based care. The issue does not appear unique to our region and is observed across the province of Ontario.

The hospital was also a frequent place of death. Half our overall patient cohort (55%) died in an acute-care hospital, and deaths at home or in hospice accounted for only 23% and 22% each. Prior studies have shown that the proportion of deaths in hospital is far lower in the United States, where integrated data from the Surveillance, Epidemiology, and End Results program and Medicare demonstrate close to half the frequency observed in our cohort. Feedback from health care professionals in our study suggests that insufficient numbers of palliative care providers and hospice beds, and variable skillsets in community health care providers, all contribute to apparent gaps in community-based end-of-life care. Those findings lend further support to the identification, in prior studies, of barriers such as lack of institutional funding, lack of consistency in care delivery across geographic regions, and misperceptions about shared care as key issues that must be addressed to increase the efficiency of community end-of-life care.

Interestingly, patients and caregivers in our cohort did not appear to attempt to contact their oncology or primary care teams before presenting to the ED—potentially because of anxiety about or acuity of the symptoms. However, that lack of contact might also represent a conditioned response concerning the use of ED services. Alternatives to ED presentation, coupled with patient education, are needed to improve that aspect of quality end-of-life care.

Our study has limitations. The sample size was relatively small, and the data represent a single health care region in Ontario and thus might reflect local practice patterns. In addition, reasons for ED visits were abstracted from ED records, limiting the amount of information obtained and the ability to discriminate between symptoms associated with lung cancer and potentially reversible presentations such as pneumonia. Nevertheless, the data appear consistent with those previously reported from provincial databases. Our request for caregiver interviews drew a low response rate, and thus the true determination of satisfaction with ED visits and end-of-life care might be at risk of selection bias. Finally, because of limitations in data collection and sample size, our study did not include a more in-depth comparative analysis of levels of palliative care access in community and academic centres, nor did it include other composite scores of aggressive end-of-life care measures such as admission to the intensive care unit.

CONCLUSIONS

Our study highlights the high use of acute-care resources, including ED visits, by lung cancer patients approaching end of life and also the high rate of deaths in acute-care facilities. Our study suggests that interprofessional and patient-provider communication, earlier connection to homecare services, and improved non-acute-care access could reduce the need for acute-care resources. The next steps in improving the quality of end-of-life care for these patients requires the evaluation of strategies to integrate palliative care earlier and to remove barriers to effective community-based end-of-life care.

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CONFLICT OF INTEREST DISCLOSURES

We have read and understood Current Oncology’s policy on disclosing conflicts of interest, and we declare that we have none.

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