



## Original Article

## Prognosis, Treatment Benefit and Goals of Care: What do Oncologists Discuss with Patients who have Incurable Cancer?

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## Abstract

**Aims:** Documentation of advance directives among patients with terminal cancer is known to be poor. Here we describe documentation of prognosis, treatment benefit and goals of care discussions in outpatients with advanced cancer.

**Materials and methods:** All patients receiving first-line palliative chemotherapy for metastatic pancreas or lung cancers during 2010–2013 at the Cancer Centre of Southeastern Ontario were identified from electronic pharmacy records. Clinical notes from medical oncology were reviewed to identify documentation of discussions regarding prognosis, treatment benefit and goals of care. Differences between groups were tested using the chi-squared test.

**Results:** In total, 222 patients were included: 80% (177/222) with lung cancer and 20% (45/222) with pancreas cancer. Medical oncology notes documented discussion of prognosis in 64% (142/222), palliative intent of therapy in 82% (182/222), magnitude of treatment benefit in 29% (64/222) and goals of care in 4% (9/222) of patients. An estimate of survival was documented in 36% (79/222) of cases. Across medical oncology providers there was substantial variation in the frequency of discussing prognosis (range 33–90%,  $P < 0.001$ ), treatment intent (range 55–100%,  $P < 0.001$ ) and goals of care (range 0–17%,  $P = 0.034$ ). In total, 41% (93/222) of patients were seen by palliative care; substantial medical oncology provider variation was observed (range 27–58%,  $P = 0.020$ ). Referral rates to palliative care did not increase over time (41–44%,  $P = 0.250$ ).

**Conclusions:** In this cohort of ambulatory patients with an estimated life expectancy of 1 year or less, medical oncology documentation of prognosis, treatment benefit and goals of care was poor. Less than half the patients were seen by palliative care. Initiatives to improve documentation and referral to palliative care are needed.

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**Key words:** Communication; goals of care; patient preferences; prognosis; quality of care

## Introduction

Documentation of advance care plans for patients while they are well enough to express themselves is an integral component of patient-centred care. The importance of documenting these plans becomes more pronounced among patients with advanced cancer and limited life expectancy. The oncologist, with an ongoing therapeutic relationship and an in-depth knowledge of patient

prognosis, is in a good position to discuss advance care plans. The American Society of Clinical Oncology (ASCO) has recognised this practice as a marker of quality care. The ASCO quality initiative recommends a documented discussion of advance directives within three visits after a diagnosis of metastatic cancer [1]. Recent guidance in the UK also emphasises the importance of discussing Treatment Escalation Plans with patients and families [2]. For patients with advanced cancer, 'code status' is infrequently documented in the outpatient setting [3–5]. Code status refers to specific patient wishes in the event of an acute medical deterioration. Treatment goals in this context can span a continuum from a focus on symptom management alone to cardiopulmonary resuscitation (CPR) and mechanical ventilation. When these patients present to hospital with an

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acute clinical deterioration, this can produce a stressful, urgent and, often traumatic, discussion between the patient, their family and the health care team that is often meeting the patient for the first time. Moreover, it places patients at risk of receiving unwanted aggressive medical interventions. Previous work has shown that having end-of-life discussions in the outpatient setting is associated with reduced use of aggressive medical care, greater use of hospice services and improved quality of life for patients and bereaved family members [6,7].

The existing literature on this topic is very limited in the outpatient setting, with only a single published study [3] and two reported abstracts [4,5]. These studies were all from single US institutions and reported code status documentation rates between 2 and 20%. Documentation of other elements such as prognosis and treatment intent was not evaluated. We undertook the current study to describe the extent to which medical oncologists document discussions regarding prognosis, treatment benefit and goals of care within a cohort of outpatients with advanced pancreas cancer and lung cancer initiating palliative chemotherapy. Understanding current practice was the first step to inform the design of a local quality improvement initiative.

## Materials and Methods

### *Study Design and Population*

This was a retrospective single institution cohort study. The study population included all patients with metastatic pancreas cancer and lung cancer treated with first-line palliative chemotherapy at the Cancer Centre of South-eastern Ontario (CCSEO) between 1 January 2010 and 31 December 2013. CCSEO is an academic comprehensive cancer centre affiliated with Queen's University in Kingston, Ontario, with a catchment population of about 500 000. Electronic pharmacy records were used to identify potentially eligible patients. Patients with locally advanced disease and no distant metastases were excluded. To be eligible patients were required to have at least four clinic visits (two of which had to be after initiation of palliative chemotherapy). The minimum clinic visit criteria were used to ensure that the study population has an existing therapeutic relationship with medical oncology and enough continuity to facilitate a discussion of prognosis, treatment benefit and goals of care. At CCSEO, outside of holidays/weekends, patients are generally seen by the same medical oncologist at each clinic visit. All medical oncology clinical notes within the electronic chart were reviewed for eligible patients from the time of consultation until two visits after the initiation of chemotherapy. All notes from palliative care providers after the initial visit by medical oncology were also reviewed. Patient demographics, disease characteristics and treatment data were captured in an electronic database by a single investigator (WR). This study was approved by the Research Ethics Board of Queen's University.

### *Study Outcomes*

The primary study outcome was written documentation of a patient's goals of care. In this study we define goals of care as the level of care a patient would like to receive in the event of an acute decompensation; this process is analogous to the documentation of a Treatment Escalation Plan in the UK. This included four options: (i) full resuscitative measures did not limit any treatments, including CPR, intubation and defibrillation; (ii) life-sustaining treatments included dialysis and vasopressors, but excluded CPR, defibrillation and intubation; (iii) full medical management included diagnostic imaging and blood tests, as well as simple therapies like antibiotics and intravenous fluids but no aggressive care; and (iv) an approach that only involved therapies directed at relieving symptoms but not reversing any underlying disease processes.

We also identified how often providers documented broader discussions around the natural history of the disease and expected outcomes. We captured if the following elements were documented in the clinical notes: whether the disease was incurable; whether treatment intent was palliative; an estimate of patient survival expressed in weeks/months; and the magnitude of benefit (in weeks/months) associated with treatment.

### *Statistical Analysis*

Data were collected in an Excel file designed for this study, and imported into IBM SPSS (Version 22.0 for Windows, Armonk, New York, 2014) for statistical analysis. Each medical oncologist and palliative care provider was assigned a study identification to allow us to explore for provider variability among the study outcomes of interest. Data were first analysed descriptively, including means and standard deviations for continuous data, and frequencies and percentages for categorical data. Comparisons across providers, as well as by patient age, gender, disease site and year, were made using the chi-squared test. Results were considered statistically significant at  $P < 0.05$ .

## Results

### *Study Population*

Electronic pharmacy records identified 376 potentially eligible patients. After chart review, 103 patients were excluded for the following reasons: other form of cancer ( $n = 5$ ); locally advanced disease ( $n = 38$ ); did not receive palliative chemotherapy ( $n = 13$ ); no medical oncology consult ( $n = 22$ ); less than four clinical visits with medical oncology ( $n = 47$ ); less than two clinical visits with medical oncology after starting chemotherapy ( $n = 5$ ). The study population therefore included 222 patients seen by medical oncology between 2010 and 2013 for palliative chemotherapy; 80% with lung cancer and 20% with pancreas cancer. The characteristics of the study population are shown in [Table 1](#). The mean age was 65 years (range 33–85)

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