

Diagnosis matters: the differing clinical trajectories for terminal prostate, lung and haematological cancers

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Background

There is a belief that end-of-life care issues are similar for all cancer patients, irrespective of their primary cancer diagnosis. This exploratory study into the terminal trajectories of three common cancers challenges this belief.

Methods

A retrospective, systematic, and mixed qualitative and quantitative medical record review of 30 deceased patients in 2010 was performed between two Victorian networks. The last 90 days of life were examined in three equally distributed cancer groups – prostate, lung and haematological.

Results

The trajectories for the three malignancies differed in temporal, symptomatic, supportive and interventional characteristics.

Discussion

Our study suggests diagnosis does indeed matter. The varying symptomatology for the different cancers markedly influenced clinical management, utilisation of palliative care services and the site of care and site of death. Our study suggests potential areas for better collaboration between general practitioners, community and specialist palliative care services. Emerging work supports our findings, but this area warrants further research.

The literature on disease trajectories to date has focused predominantly on the differing trajectories for malignancy, chronic illnesses and frailty. These three groups have very different decline trajectories.¹ However, there has been little further work on differentiating the trajectories of most cancers, apart from identifying those with generally very poor prognoses (eg pancreatic and lung cancers). Indeed, it has been suggested that 'management of the issues people face near end-of-life (EOL) are similar regardless of their main type of cancer'.²

It was our clinical impression that the trajectories for the major cancers are very different. We agree with Lunney that 'differentiating between the expected trajectories and related (care) needs would help shape tailored care'.¹ The value of such an approach has been shown in recent research around primary brain tumours, particularly glioblastoma multiforme.³ This work emphasises that, in addition to the obvious commonly occurring hemiparesis and functional decline, significant other symptoms are common. These include progressive cognitive impairment, reduced attention, short-term memory loss, personality changes and mood swings. These add an additional, often unacknowledged, burden to patient care. It also highlights the paucity of information available to patients, their carers and other healthcare professionals, resulting in the failure of, or belated access to, adequate support services.

We hypothesised that cancer type does indeed matter. The aim of this exploratory study was to describe the terminal disease trajectories for prostate, lung and haematological cancers and how these may influence site of end-stage care and site of death. We further explored how this knowledge may better inform the coordination of care across general practice, palliative care services and acute hospital care. The general practitioner (GP) is pivotal in this, but with 10,480 cancer deaths in Victoria in 2008,^{4,5}

and over 6000 GPs⁶ across the state, some GPs may have limited experience of dying cancer patients.

Methods

Patients were sampled from two Victorian Health Networks. Both were university-affiliated and centred around major teaching hospitals, and included busy oncology departments, large emergency departments, inpatient hospices and bi-disciplinary (medical and nursing) hospital palliative care consultation services.

Patients with lung and haematological cancers were selected from a metropolitan network (Monash Health) and those with prostate cancer from a major regional centre (Barwon Health).

An alphabetical list of all the patients who died in 2010 from one of the sentinel cancers was obtained from the medical record departments of the relevant networks. We sampled every 10th lung cancer death (out of 123), every 4th haematology cancer death (out of 43) and every 2nd prostate cancer death (out of 22). Ten patients from each group with the relevant diagnosis confirmed and adequate available information were selected. Data collection was restricted to the last 90 days of life, which is usually recognised to encompass the 'turning point' (ie the point when goals of care change from active, or life-prolonging, to palliation for over 90% of cancer patients).^{7,8}

Each medical record was reviewed by a palliative care physician and a social worker/social scientist with palliative care experience. Data were available from emergency department inpatient and outpatient records, but not from radiotherapy or community palliative care services. Data were entered directly into a specifically designed Microsoft Access database. Information regarding demographics, care arrangements at home, events precipitating hospital or hospice admission, dates and reasons for admission, inpatient medical management and allied health and specialist palliative care input was collected.

Quantitative and qualitative data were collected. This paper concentrates predominantly on the medical aspect of care. Further details of the methodology and a qualitative analysis are covered in a separate publication.⁹

The ethics committees of Barwon Health (Human Research Ethics Committee [HREC]11/79) and Monash Health (HREC 11204L) approved the study as a low-risk project.

Results

Results for patients with prostate, lung or haematological cancer are summarised in *Tables 1, 2 and 3*, respectively. Non-specific constitutional symptoms were variously categorised by the many different doctors looking after these 30 patients. We elected to classify fatigue, not coping and increasing dependency as equivalent terms to cover this. An EOL goal of care acknowledges it is anticipated the patient is likely to die within days.

Table 4 is a composite snapshot comparing and contrasting the differing clinical terminal trajectories.

Prostate cancer

Patients with prostate cancer (P1–P10; *Table 1*) were elderly, often with non-specific constitutional symptoms. Pain was common but generally readily controlled. The need for, or problems associated with, an indwelling catheter was neither a reason for admission nor a reason for continuing inpatient care in any of the prostate cancer patients reviewed. P3 and P10 illustrate the two extremes of the patient group.

P3 (89 years of age) was admitted from home with left leg pain and decreasing mobility. Although his pain was controlled, he became increasingly dependent and mildly confused. His wife 'was teary and expressed some self-reproach and regret at not being able to care for him at home'. He died

Table 1. Data for patients with prostate cancer

Age (years)	Age range: 67–89 Median age: 75
Symptoms	
Pain	8 (4 – reason for admission)
Fatigue/not coping/increasing dependency	9
Dyspnoea on minimal exertion	1
Moderate/severe cognitive impairment (delirium)	2
Mild cognitive impairment	5
Interventions	
Blood product support (number of episodes)	5
Surgery/IV antibiotics/chemotherapy within last 2 weeks of life	0/0/0
Total number of days of in-patient care over last 90 days	Range: 0–90 Median: 20 25th and 75th interquartile range: 45
EOLC documented as goal of care for last admission	3
Site of death	Hospital: 1 Hospice: 8 Home: 1

EOLC, end-of-life care; IV, intravenous

comfortably after a 12-week hospice admission.

P10 (70 years of age) was the only study patient to die at home. He and his wife were committed to his staying at home. He had no admission in the last 90 days and had no major symptoms. His wife was his full-time carer with support from their daughter. P10's GP visited him frequently. The community palliative care service was involved for many months

and organised a hospital bed and other aids, and daily visits in the last few weeks. Offers of respite admission to the local hospice were declined.

Of the nine hospital or hospice deaths, only three had EOL care as the goal for the last admission. When the possibility of discharge was mooted for the other six, they and/or their carers declined, stating it is 'now too difficult to care for at home'. Four were in hospital or hospice for 4

weeks or longer (including P3 for 12 weeks).

Lung cancer

Patients with lung cancer (L1–L10; *Table 2*) were generally younger, had more acute symptoms and more rapid declines. Five developed moderate-to-severe delirium and two had seizures (four had a clinical diagnosis of cerebral metastases and this was radiologically confirmed in three patients). Six developed dyspnoea on minimal exertion. The frequent occurrence of significant dyspnoea and delirium resulted in hospital admission.

Patients with lung cancer generally underwent more aggressive management, as in the case of patient L6 (76 years of age) who presented with 'not usual self' and a facial droop. A single frontal cerebral metastasis (from a primary lung adenocarcinoma) was resected. Seven weeks later, he presented again with a pathological right femoral shaft fracture. An intramedullary nail was inserted. He had a stormy post-operative course and died from post-operative pneumonia. Multiple medical specialist referrals were made but palliative care involvement occurred only the day before he died.

These patients often deteriorated rapidly, as with L3 (67 years of age) who had ceased active treatment 3 weeks earlier, presented to the emergency department clearly dying, and died 2 hours later while awaiting transfer to hospice.

Of the 10 hospital or hospice deaths, only three had an EOL care goal stated on the last admission. The terminal admissions lasted less than 1 week in five patients and the longest admission was 4 weeks. Of the six patients who died in hospices, three were transferred from the general hospital within 1 week before death, and one within 3 days of death.

Haematological cancer

Patients with haematological cancer (H1–H10; *Table 3*) had all been diagnosed for months to years. They had multiple emergency department presentations and short-term admissions for chemotherapy

Table 2. Data for patients with lung cancer

Age (years)	Age range: 54–84 Median age: 68
Gender	Male: 6 Female: 4
Non-small cell/small cell histology	6/3*
Symptoms	
Pain	4 (but not as reason for admission)
Fatigue/not coping/ increasing dependency	1
Dyspnoea on minimal exertion	6
Moderate/severe cognitive impairment (delirium)	5
Generalised seizures	2
Interventions	
Surgery	Excision of solitary cerebral metastasis: 1 IM nail fractured femur: 1 Pleurodesis: 1
Blood product support (no. of episodes)	4
IV antibiotics	3
Chemotherapy (within last 2 weeks)	Given: 1 Considered: 2
Continued established peritoneal dialysis	Ceased 4 days before death: 1
Total no. of days of inpatient care over last 90 days	Range: 1–59 Median: 5 25th and 75th interquartile range: 14
EOLC documented as goal of care for last admission	3**
Site of death	Hospital: 4 (ED: 1) Hospice: 6 Home: 0

ED, emergency department; EOLC, end-of-life care; IM, intramedullary; IV, intravenous

*L4 had no tissue diagnosis

**includes L8 transferred for EOL hospice care from another network 8 days before death

and/or blood product support. Their deaths were often precipitous and associated with late medical interventions; one patient (H2) received chemotherapy 24 hours before his death.

H5 (58 years of age) illustrates the diagnostic dilemmas and aggressive treatments common in haematological cancer patients. After initial diagnosis and treatment for bacterial meningitis, relapsed cerebral lymphoma was diagnosed. High-dose methotrexate was ineffective, and complicated by neutropenic sepsis and agitated delirium. A 6-week course of antibiotics provided minimal benefit and he was discharged for EOL hospice care, where he died 3 days later.

H8 (76 years of age) illustrates the very rapid decline commonly seen. This man was receiving chemotherapy for multiple myeloma. He presented to the emergency department from home, requiring an intensive care unit (ICU) admission because he had pneumonia and acute renal failure. He died in the ICU 3 days later with no palliative care referral.

The majority of patients with haematological cancer had belated palliative care referrals, whereas three patients had none. Despite the long trajectories, only two had been referred to community palliative care services. Of the seven patients who died in hospice, five were transferred from the general hospital 1 week or less before death, and three died within 3 days.

Discussion

Our findings, summarised in *Table 4*, show very different trajectories for the three types of cancer.

Patients with prostate cancer in our study deteriorated over many months. They rarely required aggressive medical inpatient management. However, their increasing dependency and often frail/elderly spouses, meant most died after a hospice admission of at least 1 month. This finding is supported by Gott who stated that 'older people identify significant barriers to dying at home and often report preferences for care in hospital, feeling reassured by the

presence of medical expertise/technology available in hospitals'.¹⁰

By contrast, the lung cancer patients developed significant acute symptoms, particularly dyspnoea and moderate-to-severe delirium, precipitating inpatient management. It is interesting to note, disappointingly, that palliative care services were generally involved late or not at all. Temel's definitive paper, published in 2010, found concurrent palliative care and oncology management

of patients diagnosed with metastatic non-small cell lung cancer resulted in improved quality of life and a statistically longer median survival.¹¹

Haematological malignancies are known to have prolonged ongoing acute management and, frequently, late interventions.¹² Our findings showed the same patterns. Patients have a long course from diagnosis but generally a very rapid rate of decline for which they are often not prepared. Palliative care referrals

Table 3. Data for patients with haematological cancer

Age (years)	Age range: 58–84 Median age: 75
Gender	Male: 7 Female: 3
Lymphoma/CML/multiple myeloma	5/3/2
Symptoms	
Pain	2 (1 – reason for admission)
Fatigue/not coping/increasing dependency	3
Dyspnoea on minimal exertion	1
Moderate/severe cognitive impairment (delirium)	2
Mild cognitive impairment	1
Interventions	
Surgery	Frequent PICC lines
Blood Product Support (no. of episodes)	17
IV antibiotics	7
Chemotherapy (within last 2 weeks)	Given: 2 Considered: 1*
ICU admission	1 (patient died in ICU after 3 days)
Total no. of days of inpatient care over last 90 days	Range: 3–90 Median: 19 25th and 75th interquartile range: 27
EOLC documented as goal of care for last admission	2**
Site of death	Hospital: 3 (ICU: 1) Hospice: 7 Home: 0

CLM, chronic myeloid leukaemia; EOLC, end-of-life care; ICU, intensive care unit; IV, intravenous; PICC, peripherally inserted central catheter

**Includes H2 given chemotherapy within 24 hours of death*

***H3 transferred for EOL hospice care from another network 4 days before death, and H10 admitted directly to hospice from home for EOLC*

are frequently belated and leave little time to form meaningful relationships with patients/families, or to optimise the place of death.

Despite evidence that many terminally ill patients would prefer to die at home,^{13,14} this can be challenging. In Australia, most patients with cancer die in a hospital/hospice.⁴ Gomes and Higginson identified six factors influencing death at home:¹⁴

- patient's functional status
- preference for death at home
- availability of professional support
- intensity of professional support
- living with relatives
- support available from their extended family.

A recent Italian study also identified dyspnoea and delirium as major predictors of hospitalisation.¹⁵ In this study, GPs,

palliative medicine specialists and community palliative care services worked collaboratively to provide educational support to patients, families and community services. Simple and clear management guidelines were also developed, enabling the pre-emptive management of potential out-of-hours crises and subsequent avoidance of inpatient admissions.

There are potential limitations to our study. It was retrospective; the outcome (death) was known; numbers were low; there were potentially different interpretations of the medical record; and it could not capture non-documented discussions nor patient management outside the networks, especially radiotherapy, community and GP records. Its strengths, however, are

in its systematised depth of review of the whole medical record, as well as the random selection of patients from network-wide databases.

In conclusion, we suggest the assumption that all patients with terminal cancer have similar care needs is not valid. The wider appreciation of the likely trajectories for the common cancers should help inform care of patients with terminal cancers and facilitate optimal collaboration between all of the services involved.

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Table 4. Summary of the clinical terminal disease trajectories for the three different cancers

Cancer Type	Prostate	Lung	Haematological
Symptoms	Non-specific constitutional symptoms with steadily increasing dependency for ADLs	Severe dyspnoea, moderate to severe cognitive impairment	Acute, late in illness
Medical interventions	RBC transfusions, other interventions rare	Relatively frequent medical/surgical interventions including palliative chemotherapy	Chemotherapy and blood product support common
Admissions	Long, often for frailty	Short	Multiple, short, acute
Trajectory	Long	Short	Long
Rate of decline in end stage	Slow	Fast	Very fast
Palliative care input	All had significant palliative care input	8/10 had moderate palliative care input	3/10 had no palliative care referral, the others generally belated referral
Time between palliative care referral and death (days)			
Range	30–360	0–49	0–46
Median	30	7	4
25/75 interquartile range	60	7	14
Community palliative care referral	8/10	5/10*	2/10
Site of death			
Hospital	1	4 (ED: 1)	3 (ICU: 1)
Hospice	8	6	7
Home	1	0	0

ADL, activities of daily living; ED, emergency department; ICU, intensive care unit; RBC, red blood cells;

*1 patient declined a community palliative care referral

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