



Hospital cancer deaths: late diagnosis and missed opportunity

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Accepted 22 July 2011

Published Online First
24 August 2011

ABSTRACT

Objectives To establish factors that influence and contribute to the death of patients with cancer in acute hospitals in Northern Ireland.

Design Retrospective clinical note review.

Setting 16 acute hospitals, covering 5 Health and Social Care Trusts across Northern Ireland.

Participants 793 adult patients with cancer who died in an acute hospital between July and December 2007 identified through the Northern Ireland Cancer Registry. Information was available for 695 (88%).

Results Three main reasons for acute hospital deaths were uncovered. First, 26.3% of patients were diagnosed with cancer during their last hospital admission. These patients were significantly different from the rest of the sample in being older, not partnered, having more comorbidities and fewer hospital admissions in their last year of life (all $p < 0.001$).

Second, patients were very ill with 78.7% admitted as an emergency, requiring medical attention as a result of cancer-related (37.4%) and urgent physical symptoms (33.5%). Third, despite 38.3% of patients specifically requesting discharge to their usual residence, hospice or other hospital, this was not achieved. For 76.3%, this was owing to a deterioration in their medical condition. However for 12.4% there was a lack of a suitable bed, a care package was not in place for 4.9% and 3.0% lacked the required family support. In addition, preferred place of death was only recorded for 41% of patients.

Conclusions Late diagnosis of cancer is a problem which requires further research. Training should be in place to ensure that a patient's preferred place of death is discussed, recorded and made part of routine end of life care. To achieve this, all medical staff should know when a patient is dying. Further research is required to establish what enables patients with cancer to die at home.

INTRODUCTION

Over 151 000 cancer deaths occur in the United Kingdom every year.¹ Issues pertaining to end of life (EoL) cancer care, such as the appropriate use of interventions, access to specialist palliative care, and dying in one's place of choice, affect these patients and their families. EoL care has been defined by the Department of Health, England² as care that "Helps all those with advanced, progressive, incurable illness to live as well as possible until they die. It enables the supportive and palliative care needs of both patients and family to be identified and met throughout the last phase of life and into bereavement. It includes the management of pain and other symptoms and provision of psychological, social, spiritual and practical support." National Institute of Clinical

Excellence (NICE) guidelines for supportive and palliative care recognise that the provision of community care may lead to fewer crises, fewer hospital admissions, more rapid discharges and thus more patients being enabled to die in their place of choice.³

The majority of patients with cancer would like to die in their own home,^{4–8} yet 51% of patients in England and Wales,⁹ 52% in Scotland,¹⁰ and 46% in Northern Ireland die in hospital (N. Ireland Cancer Registry Data, 2007). Within our ageing population, projections show that institutional deaths are set to increase to 66% by 2030.¹¹ Facilitating preferred place of death (PPD) is a key feature of good EoL care. Over recent years, acute hospitals have been seen as an inappropriate place for the death of patients with cancer¹² as they are not designed or equipped for the holistic approach that EoL care requires.

Systematic reviews have identified predictors of place of death categorised into factors relating to illness, demographic and personal variables, healthcare input, social support and historical trends.¹³ Factors such as a long duration of disease, low functional status, good social conditions and support and stating a preference to die at home, use of homecare support, a higher level of intervention and living in a rural setting were all associated with home deaths. Factors associated with hospital death were inpatient bed availability, prior hospital admissions, living in areas with a greater hospital provision and ethnicity.¹³ Patients with haematological cancer are more than twice as likely to die in hospital as those with other cancer types.¹⁴ Murray and colleagues,¹⁵ found similar results to those reported by Gomes and Higginson,¹³ although they emphasise that findings are inconclusive. Providers are keen to bridge the gap between preferred and actual place of death of patients with cancer. Thus, this detailed examination of cancer patients' clinical records where death occurred in acute hospitals provides data on the factors associated with a hospital death in a UK population.

METHODS

Following ethical approval, the Northern Ireland (NI) Cancer Registry conducted a retrospective medical note review of all adult patients with cancer who died within an acute hospital setting in NI between July and December 2007.

Data collection

In addition to routine medical and demographic information, detailed data were collected on last

hospital admission, investigations, treatments, level of palliative professional involvement, expectation of death, preferred place of death (as recorded within medical notes), and the number of previous hospital admissions within the last year of life. Expectation of death was noted if it had been explicitly recorded within the medical notes in discussions with the patient, relatives or carers; or for the attention of staff such as enrolment on the Liverpool Care Pathway. Reasons for hospital admission were categorised by the Registry staff following discussions with a Macmillan GP. Macmillan GPs are specialist palliative care GPs, funded by the cancer charity. Their role is to educate other GPs and multiprofessional groups about palliative care, as well as contributing to strategic planning of palliative and EoL care. Categorisation was based on each patient's age, gender, existing comorbidities, known cancer diagnosis, symptoms on admission, relevant contents of the GP referral letter (where available) and cause of death. Data were entered onto a secure digital proforma and protected by biometric (fingerprint) authentication and hardware encryption. Following transfer onto SPSS database and data cleaning, χ^2 analysis was used to assess the statistical significance of categorical data while Mann–Whitney and Kruskal–Wallis were used for continuous data. All averages are reported as medians with interquartile range (IQR).

RESULTS

NI Cancer Registry data

In 2007, there were a total of 4108 cancer deaths within NI. Registry data show that 45.5% of these patients died in hospitals, 34.1% died at home, 12.5% in hospices and 7.9% in nursing, residential or care homes.

Patient characteristics

During the last 6 months of 2007, a total of 793 adult patients with cancer died in an acute hospital. Owing to medical notes being unavailable, not found, or lacking sufficient information, data were collected on 695 (88%) patients in 16 acute hospitals throughout all five NI Health and Social Care Trusts (HSCTs). Details were compared for included and excluded patients. Significantly more men were excluded (67.0%) from the study than included (53.4%; $p=0.01$), but no other significant differences were found.

The median age of patients was 74 (IQR=17) years, with 53.4% being male and 54.7% partnered (table 1). As determined by area postcode, the majority of patients were from more deprived areas (quintiles 1 and 2). Similar to the general cancer population in NI, most of the sample comprised patients with cancers of the digestive organs and respiratory and intrathoracic organs. A total of 87.9% of patients had comorbidities, the most common being hypertension, cardiovascular disease, chronic obstructive pulmonary disease, diabetes and arthritis. Cancer stage was recorded for 63.2% of patients and the majority (82.0%) had stage IV disease.

Hospital admissions: last year of life

Patients had an average of two (IQR=2) hospital admissions in their last year of life. Patients with no prior admissions (32.7%) were significantly older (77 years) than those who had been previously admitted (72 years; $p<0.001$). Partnered patients were more commonly observed to have multiple admissions. Prior admissions also varied significantly by cancer diagnosis ($p=0.009$). Patients with cancers of the male genital organs (78.9%) and digestive organs (73.6%) had prior admissions,

whereas fewer patients with breast cancer (48.3%) had admissions in their last year of life.

Patients spent an average of 21 (IQR=25) days in hospital in their last year of life, with 11 (IQR=18) days on their last admission. Patients without a partner spent significantly more days in hospital during their last year of life (25 days) than patients who were partnered (20 days, $p=0.004$).

Final hospital admission

On patients' final hospital admission, the most common source of referral was a GP (46.2%) or the patient/patient's family (19.0%), with over half (51.8%) occurring during practice hours (08:30–18:00). Most (78.7%) were emergency admissions with either cancer-related (37.4%) or urgent physical

Table 1 Patient characteristics

Patient characteristics (n=695)	N (%)
Gender	
Male	371 (53.4)
Female	324 (46.6)
Age (years)	
≤45	27 (3.9)
46–60	89 (12.8)
61–70	159 (22.9)
71–80	237 (34.1)
≥81	183 (26.3)
Marital status	
Partnered	380 (54.7)
Not partnered	313 (45.0)
Unknown	2 (0.3)
Socioeconomic status	
Quintile 1 (most deprived)	165 (23.7)
Quintile 2	158 (22.7)
Quintile 3	125 (18.0)
Quintile 4	122 (17.6)
Quintile 5 (least deprived)	124 (17.8)
Unknown	1 (0.1)
Cancer type (ICD-10 codes)	
Digestive organs (C15C26)	182 (26.2)
Respiratory and intrathoracic organs (C30–C39)	170 (24.5)
Breast (C50)	58 (8.3)
Female genital organs (C51–C58)	35 (5.0)
Male genital organs (C60–C63)	38 (5.5)
Other (C00–C14, C40–C49, C64–C97)	212 (30.5)
Comorbidity	
Alzheimer's disease	46 (6.6)
Arthritis	87 (12.5)
Cardiovascular disease	120 (17.3)
Cerebrovascular disease	57 (8.2)
COPD	97 (14.0)
Diabetes	95 (13.7)
Hypertension	236 (34.0)
Learning disability	7 (1.0)
Parkinson's disease	16 (2.3)
Psychiatric disorder	16 (2.3)
Renal disease	30 (4.3)
Multiple sclerosis	1 (0.1)
Other malignancy	70 (10.1)

COPD, chronic obstructive pulmonary disease.

(33.5%) symptoms. Patients had an average of four symptoms on admission, most commonly pain (48.3%), breathlessness (40.9%), anorexia (40.4%) and nausea/vomiting (33.8%).

Patients admitted as an emergency were significantly older (74 years, IQR= 16) than those with a non-emergency/planned admission (70 years, IQR=17; $p=0.003$) and a significantly higher percentage were not partnered (47.2%) compared with others (36.5%; $p=0.02$). Patients admitted as an emergency were mainly admitted with cancer-related (41.1%) or urgent physical symptoms (40.6%), whereas patients with a non-emergency/planned admission were mainly admitted for treatment (35.8%), cancer-related symptoms (23.6%) or for further investigations/as precaution (17.6%).

Seventy (10.1%) patients were admitted from a nursing home, of whom 52.9% were admitted within GP practice hours, with most being referred by either a GP (44.3%) or nursing home staff (40.0%). Reasons for admission were mainly urgent physical (62.9%), followed by cancer-related (20.0%), further investigations/as precaution (10.0%), for palliative care (4.3%), or for treatment (2.9%). Average length of stay from admission until death for nursing home patients was 9 (IQR= 17) days. Over one-third (35.7%) of patients admitted from a nursing home were diagnosed on their last hospital admission.

Overall, 72 (10.4%) patients had surgery during their last year of life, an average of 19 (IQR= 97) days before death. Of those patients, 44 (61.1%) had surgery on their last admission, an average of 10 (IQR=17) days before death. Of these patients 16 (36.4%) were diagnosed on their last admission. Patients underwent surgery for symptom control (43.2%), diagnosis/treatment of cancer (38.6%), or fracture repair (18.2%). Only a very small percentage of patients had chemotherapy (3.9%) or radiotherapy (4.9%) on their last hospital admission.

Patients diagnosed on last admission

Over one-quarter, 26.3% ($n=183$), of patients were diagnosed with cancer on their last hospital admission. These patients were significantly older (79 years, IQR=13) than those with a prior diagnosis (71 years, IQR=16; $p<0.001$). Their cancers were predominantly those of the respiratory and intrathoracic organs (29.0%) and those of the digestive organs (24.6%). Patients diagnosed on their last admission tended to be admitted with urgent physical symptoms (63.4%) or for further investigations/as precaution (23.0%) compared with the rest of the sample (22.9%, 6.3% respectively; $p<0.001$). The most common symptoms on admission were similar to those of the main sample; however significantly more experienced anorexia (50.8%) and weight loss (45.9%) compared with the rest of the sample (36.7%, 17.4% respectively). Patients diagnosed on their last admission had more comorbidities, but fewer admissions in their last year of life (both $p<0.001$). For 56.3% of the patients diagnosed on their last admission, this was their only hospital admission within that past year. The median time from admission to diagnosis was 6 (IQR=10) days, while survival from diagnosis until death was 11 (IQR=15) days.

Deaths within 48 hours of admission

Approximately 14% ($n=98$) of patients died within 48 hours of being admitted to hospital and significantly more of these patients (42.9%) had specialist palliative care services at home in contrast to 28.8% within the remaining sample. However, over half of those with home specialist palliative care were admitted outside of normal GP practice hours (59.5%). The median age of patients who died within 48 h of admission

was not statistically different from the remaining sample. The majority of these patients had a cancer diagnosis before their final admission however, 8.2% were diagnosed within 48 hours of death. Patients experienced similar symptoms on admission to those in the main sample but a significantly higher percentage experienced breathlessness (53.1%) compared with the remaining patients (46.9%; $p=0.008$). A significantly higher percentage were not partnered (70.1%) compared with the remaining sample (52.5%; $p=0.001$).

Death was expected for 85% of patients who died within 48 hours of admission. 'Do not attempt resuscitation' (DNAR) orders were in place for 91.1% ($n=633$) of all patients.

Although death was expected for 92% of patients in this study and DNAR orders in place for 91.1%, PPD was recorded for less than half (40.7%) of the patients. Where recorded, the majority of patients preferred to die at home (61.1%), followed by hospice (14.5%), hospital (12.7%) and nursing home (11.7%), which for many patients, is home. More older patients, preferred a nursing home death, particularly those over 81 years of age (28%). Conversely, younger patients had the highest percentage preference for a hospital death (≤ 45 years and 46–60 years; 25% and 20% respectively). The median age of patients who preferred to die at home was 72 (IQR=16) years, 71 (IQR= 20) years for those with a preference to die in hospital and similarly, 71 (IQR= 15) years for those who preferred to die in a hospice, while 83 (IQR=11) years was the median age of patients with a preference to die in a nursing home ($p<0.001$). PPD did not vary significantly by gender, marital status, cancer type, geographical area of residence, socioeconomic status, religion or number of previous hospital admissions in the last year of life.

A total of 266 (38.3%) patients requested discharge to their usual residence, hospice or another hospital. For three quarters (76.3%) of cases, their condition deteriorated and discharge was not possible. There was a lack of suitable beds for 12.4% of patients and the necessary care package was not in place for 4.9% while 3.0% lacked the required family support.

Specialist palliative care involvement and distance from usual residence to nearest hospice

A total of 67.1% of patients were recorded as having specialist palliative care while in hospital, with no significant differences observed between HSCTs. Specialist palliative care involvement in the community was recorded for 39.6% of patients and the provision of these services did vary significantly by HSCT. Using postcodes, we found that patients lived a median of 9.4 miles from the nearest hospice, 53.6% of patients lived within 10 miles of a hospice, 24.3% within 11–20 miles, 12.5% within 21–30 miles and 9.6% lived over 30 miles from their nearest hospice.

DISCUSSION

This study examined the medical notes of all patients with cancer who died within an acute hospital within the last 6 months of 2007 and identified three main reasons why the majority of patients with cancer die in hospital, despite most preferring to die at home.

The first, an unexpected revelation, is that over one-quarter (26.3%) were diagnosed with cancer during their last hospital admission. For these patients, the median time from admission to diagnosis was 6 days and survival from diagnosis until death, 11 days. They were significantly different from the rest of the sample, being older, not partnered, having more

comorbidities and fewer hospital admissions in their last year of life. A recent study¹⁶ of patients who died within 30 days of a breast or colorectal cancer diagnosis in Scotland (2003–7), concurred with findings in terms of age and comorbidities but in contrast, reported significantly more previous hospital admissions. Almost 300 000 new cases of cancer are diagnosed (excluding non-melanoma skin cancer) in the UK each year.¹ Death in the first month following diagnosis in England has been reported at approximately 10% for colorectal cancer, 23% for lung, 2% for breast and 12% for ovarian.¹⁷ This highlights the need for earlier diagnosis of cancer.

Older patients with a history of comorbidities may experience symptoms that mask cancer, leading to a delay in seeking medical attention. A large Danish cohort study which assessed the impact of comorbidities and cancer stage at diagnosis, found that a higher percentage of patients with severe comorbidities were found to have advanced cancer at diagnosis and higher mortality.¹⁸ In our study, one in 10 patients was admitted from a nursing home, of whom 35.7% were diagnosed on their last admission. The question remains whether death within 1 month of diagnosis is a result of delays in patient presentation, patient referrals, biologically aggressive disease or the complications associated with treatment.¹⁵

The second finding was that these patients were ill with over three-quarters (78.7%) admitted as an emergency, with cancer-related (37.4%) and urgent physical symptoms (33.5%). Over half (54.5%) were referred by a GP, 49.9% during practice hours. Where their diagnosis was not available, appropriate investigations were instigated. Where patients' diagnosis and prognosis was clear, appropriate steps were taken to ensure optimum care and where possible, to meet the patient's wishes. However, recording patients' preferred place of death was poor, even though there was a realistic expectation of death for most as evidenced by DNAR and expected death notices. These findings are in contrast to the National Audit Office's hospital note review of all adult patients with cancer who died in a Sheffield NHS teaching hospital in October 2007¹⁹ which found that 40% of patients did not have medical needs that required them to be in hospital at the point of admission and could have been cared for elsewhere. A more recent medical note review (n=593) of all patients that died within 1 year in a general hospital in England, concluded that one-third (33%) of patients could have been cared for at home if excellent EoL care services had been in place.²⁰ Our study did not assess the appropriateness of hospital admission, so direct comparisons may be misleading.

Patients in our study had an average length of stay of 11 days with 14% of patients dying within 48 hours of admission. This is a much lower figure than the 23% who died within 48 hours of admission to a general hospital in the South West of England.²⁰ The average number of hospital admissions within the last year of life was two and patients spent a median of 21 days in hospital in their last year of life. A statistical model which simulated the cost of caring for patients with cancer in their last year of life in England found that a 10% reduction in emergency admissions coupled with a 3 day reduction in length of hospital stay could equate to a saving of £104 million per year.²¹ These all add support for the recommendation that all out-of-hours teams should be trained in EoL care, as well as being able to identify dying patients.²² Availability of community services may reduce the number of emergency admissions, deaths in hospital and admissions in the last year of life. Savings from reduced emergency admissions could be redirected into community and EoL care

services, although cost savings relating to reduced admissions and length of hospital stay have yet to be established and further evaluations of community care costs are necessary.

The third finding relates to lack of facilities. For 17.3% of patients who requested discharge to their usual residence, hospice or other hospital, facilities were not available and 3.0% lacked family support. The implementation of rapid discharge services as recommended within the 2008 End of life Care Strategy,² may enable patients to die in their preferred place of care. Marie Curie Cancer Care's "Delivering Choice" programme gives terminally ill patients the choice of dying at home by providing rapid response teams for home visits during twilight and out of practice hours. The project also incorporated dedicated discharge nurses to facilitate speedy discharge. A report, published in 2008, evaluating the programme²³ found that 42% of patients that accessed the service died at home, in contrast to 19% who did not access the service.

Preferred place of death was recorded for 40.7% of patients. The large majority of these (72.8%) indicated a preference to die at home or in their nursing home, with only 12.7% of the sample preferring to die in hospital. Enabling patients to die outside hospital is complex. Research appears to indicate that important factors influencing cancer deaths outside of hospital include good social conditions, support and the availability, use and the intensity of homecare.¹³ Two Danish studies found that home deaths were associated with GP home visits and to a lesser extent, with community nurse visits.^{24 25} Both studies concluded that future research should examine the exact mechanisms of involvement and role of the GP, particularly the interface between GPs and other healthcare providers. Identifying impending death and communication with patients and their carers may be key factors facilitating dying in preferred place of death.

Enabling a patient to die at home requires symptom control, availability of specialist palliative care services, facilities, equipment and out-of-hours services. Specialist palliative care is provided in NI through 70 specialist inpatient beds in hospices and palliative care units, via hospital-based services, via community teams and through day care. Our findings show that over two thirds of the sample received specialist palliative care while in hospital. However, provision of specialist palliative care in the community was much less and varied by HSCT. While 14.5% of patients indicated that they had preferred to die in a hospice and most lived within 20 miles of a hospice, findings indicate that this was not achieved mainly because of a deterioration in the patient's condition or a lack available bed space.

CONCLUSION

Late diagnosis of cancer may have resulted in short survival and hospital death. Further work is warranted to confirm such links. Awareness of cancer as a possible diagnosis, especially among the elderly, is required. Although earlier diagnosis may not result in cure, it may allow interventions to alleviate symptoms, address quality of life issues and involve community services. Patient's preferred place of death should be discussed and recorded as part of routine EoL care. There is a need to ensure that staff are trained in the timely identification of dying patients and that all hospitals have rapid discharge programmes to facilitate, where possible, patients' and their carers' wishes. When interpreting the findings of this study, the reader should be aware of the limitations of its retrospective design and that data depended on patients' medical notes.

Although this study did not assess the appropriateness of each admission, patients with cancer who are admitted to hospital and then die are very ill. However, 8% could have returned home if facilities had been available. The problem of late cancer diagnosis prevents patients receiving appropriate palliative care services. These results provide additional evidence for action as defined in NICE guidelines³ and various EoL care strategies.^{2 22}

Acknowledgements This project was funded by the Ulster Cancer Foundation. The work of the Northern Ireland Cancer Registry is funded by the Public Health Agency.

Competing interests None.

Provenance and peer review Not commissioned; externally peer reviewed.

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