

Care of people dying with malignant and cardiorespiratory disease in general practice

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SUMMARY

Background: Provision of palliative care for people dying with malignant disease is a well-characterised aspect of general practice workload. The nature of end-of-life care of people with non-malignant disease is less well described.

Aim: To compare the general practice care provided in the last year of life to people who died with malignant and with cardiorespiratory disease.

Design: Case record review.

Setting: Two Leicestershire general practices: one inner-city, one semi-rural; total practice population 26 000 people.

Method: General practice review of the records of all people registered with the practices who died with malignant or cardiorespiratory disease between 1 August 2000 and 31 July 2002 to determine: cause and place of death, recorded comorbidity, palliative medication prescribed, number of consultations and continuity of care, receipt and duration of palliative care.

Results: When compared with people who died with cardiorespiratory disease, those who died with malignant disease were more likely to have had a terminal phase of their illness identified and to have been prescribed more palliative drugs. Both groups consulted a similar number of times, experienced similar continuity of care, had similar comorbidity, and were equally likely to die at home.

Conclusion: People who died with cardiorespiratory disease were less likely to be in receipt of formally identified terminal care and were likely to have had fewer drugs prescribed for palliation than people with malignant disease, yet they make similar demands of practices. They are likely to have unmet needs with respect to palliation of symptoms.

Keywords: cancer; cardiovascular disease; general practice; respiratory disease; terminal care.

Introduction

MOST hospice-, hospital-, and primary care-based palliative care is directed at people with cancer, while people dying of non-malignant disease have little or no access to such care. This has led to people with end-stage non-malignant disease being described as the 'disadvantaged dying'.¹⁻⁶ This may be because of difficulty in establishing an exact prognosis for people with non-malignant disease, difficulty in identifying a 'terminal phase', or poor understanding of the needs of people with non-malignant disease.^{7,8} People who are dying of non-malignant disease need palliative care,⁹⁻¹⁵ but, in contrast to palliative care for malignant disease in primary care,¹⁶⁻¹⁸ there is little published research on such provision by general practices for people with non-malignant disease, and how care differs between the two groups. This study describes the care provided by two general practices in the last year of life to people who died with malignant and chronic cardiorespiratory disease, with the aims of determining whether the care they received was different, and if so, in what ways. This study was thus an exploratory study to inform the development of hypotheses. Chronic cardiorespiratory disease was chosen as the 'index' non-malignant diagnosis because it is an important cause of morbidity and mortality, and people with end-stage cardiorespiratory disease are known to have unmet needs.^{2,8,11-15,19}

Method

Setting

The study was conducted in two practices that aim to provide high-quality, multidisciplinary palliative care to people with cancer. Both are large postgraduate training practices of approximately 13 000 patients, and have engaged with recent National Health Service (NHS) reforms (for example, personal medical service pilots²⁰), to further improve the care provided. Both practices have access to a large extended primary healthcare team 'on-site'; one has six full-time and three part-time general practitioners (GPs), and usually one GP registrar, and serves a deprived inner-city population with a sizeable minority ethnic population; the other has five full-time and three part-time GPs, and usually two GP registrars, and serves a semi-rural population. Both practices are committed to, and have invested in, providing high-quality general medical services, although the latter practice has a particular interest in cancer care.

Subjects

All patients of the practices who had died between 1 August 2000 and 31 July 2002 were identified from the

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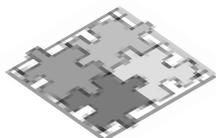
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HOW THIS FITS IN*What do we know?*

People who die with non-malignant disease have unmet needs. There is little published quantitative research on the general practice care of people who die with non-malignant disease.

What does this paper add?

People who die with cardiorespiratory disease consult as often as people with malignant disease in the last year of life, they are less likely to have a terminal phase of their illness identified and they receive fewer drugs for palliation of symptoms.



- Demographic details
- Diagnosis: carcinoma, chronic obstructive pulmonary disease (COPD), congestive cardiac failure (CCF)
- Dates of: death, diagnosis, start of palliative care^a
- Record of whether palliative/terminal care provided^b
- Recorded comorbidity
- Each consultation in the last 12 months of life: date, person, site, related to index diagnosis
- Medication at last GP contact or hospital/hospice letter

^aDated record stating that palliative care has been, or is to be, introduced. ^bAny mention in the record of the patient being in receipt of palliative care.

Box 1. Data extracted from medical records.

practices' cumulative 'death registers' and their death certificate counterfoils. Those whose cause of death was cancer or chronic cardiorespiratory disease were included, while those who had experienced a sudden or unexpected death due to myocardial ischaemia or stroke were excluded. The records of all those whose death was 'unknown' or 'unrecorded' were reviewed by the collaborating doctor in each practice to determine the likely cause of death, and were included if death was attributed to malignant or chronic cardiorespiratory disease.

Data extraction

The aim of the medical record review was to determine what medical conditions people experienced at the end of life (comorbidity), which palliative medication was prescribed, the frequency of contact with GPs, and the continuity of care provided, so that we could compare the care provided with that of people who died of malignant and chronic cardiorespiratory disease.

A medical record review form was developed, piloted, and further refined from a tool originally developed in the Centre for Cancer and Palliative Care Studies in the Institute of Cancer Research, London (Box 1). The list of drugs of interest was compiled by review of the *British National Formulary (BNF)*²¹ and the *Palliative Care Formulary*,²² and identification of all drugs in *BNF* sections relevant to control of symptom relief of people with cancer and cardiorespiratory disease.

Medical records were reviewed by a member of each practice's staff who was trained by one of the researchers. The completed forms were reviewed by the collaborating GP from each practice until he/she was satisfied that the data extraction was complete and accurate. Twelve months after the start of data extraction a 10% sample of records was checked by the practice collaborators to ensure accuracy of data extraction. No other patient records were reviewed.

Data management

The medical record data extraction forms were returned to the study team. The data were coded, double-entered, and verified. The total number of recorded consultations and number of consultations by doctors in the last 12, 6, and 3 months, and the last month of life were calculated. Drugs were grouped by *BNF* section,²¹ and presented both as a number and proportion of all drugs prescribed to people with cancer and non-malignant disease, and whether or not a patient had received any drug from each group. Continuity of care was calculated as the percentage of consultations with the most frequently consulted single doctor, two doctors, and three doctors in the last year of life.²³ Summary descriptive statistics were then generated from the data. Data were compared using χ^2 (for categorical data), Mann-Whitney U and two-sample *t*-tests (for non-parametric and parametric data respectively) as appropriate using SPSS v.11.0.1. The study was approved by Leicestershire Local Research Ethics Committee.

Table 1. Place of death by cancer and non-malignant disease.

| Place of death | Cancer <i>n</i> (%) | Non-malignant disease <i>n</i> (%) | Total <i>n</i> (%) |
|-------------------------------|---------------------|------------------------------------|--------------------|
| All hospitals | 58 (54) | 32 (70) | 90 (58) |
| Hospital | 45 (42) | 30 (65) | 75 (49) |
| Cottage hospital | 12 (11) | 2 (4) | 14 (9) |
| Private hospital | 1 (1) | | 1 (1) |
| Nursing/residential home | 9 (8) | 2 (4) | 11(7) |
| Hospice | 19 (18) | | 19 (12) |
| Home | 21 (19) | 11 (24) | 32 (21) |
| Information missing/not known | 1 (1) | 1 (2) | 2 (1) |
| Total | 108 (100) | 46 (100) | 154 (100) |

Table 2. Numbers of people with cancer and cardiorespiratory disease who were prescribed palliative medications.

| Name | BNF reference | Cancer <i>n</i> (%) | Non-malignant disease <i>n</i> (%) | <i>P</i> -value ^a |
|-----------------------|---------------|---------------------|------------------------------------|------------------------------|
| Laxatives | 1.6 | 45 (42.9) | 9 (19.6) | 0.006 |
| Diuretics | 2.2 | 27 (25.7) | 25 (54.3) | <0.001 |
| Benzodiazepines | 4.1 | 9 (8.6) | 4 (8.7) | 0.6 |
| Antipsychotic drugs | 4.2 | 8 (7.6) | 1 (2.2) | 0.2 |
| Antidepressants | 4.3 | 12 (11.4) | 2 (4.3) | 0.2 |
| Antiemetics | 4.6 | 36 (34.3) | 1 (2.2) | <0.001 |
| Non-opiate analgesics | 4.7.1 | 65 (61.9) | 26 (56.5) | 0.4 |
| Opiate analgesics | 4.7.2 | 60 (57.1) | 6 (13) | <0.001 |
| Analgesics | 4.7 | 86 (81.9) | 28 (60.9) | 0.01 |
| NSAIDs ^b | 10.1 | 24 (22.9) | 2 (4.3) | 0.004 |
| Saline nebulas | 3.2 | 4 (3.8) | 4 (8.7) | 0.2 |
| Oxygen | 3.6 | 6 (5.7) | 17 (37.0) | <0.001 |
| Dexamethasone | 6.3 | 19 (18.1) | 0 (0) | 0.001 |
| Antiepileptics | 4.8 | 3 (2.9) | 0 (0) | 0.3 |

^aDifference between proportion of patients with cancer and non-malignant disease prescribed each drug/group (χ^2). ^bNon-steroidal anti-inflammatory drugs.

Results

Medical record review

The records of 154 people who died with cancer (108 [70%]), or of non-malignant disease (46 [30%]) were reviewed. Of these, 88 (57%) were male and the average age at death was 74 years (range 37–97), with no statistical difference between those who had died with malignant and chronic cardiorespiratory disease. There was no recorded comorbidity in 74 of the records reviewed, one comorbidity recorded in 43, two in 17, and three in 10. Ten people had four or more comorbidities recorded. There was no significant difference in the number of comorbidities recorded between those who died with cancer and non-malignant disease. The most frequently recorded comorbidities were cardiac disease ($n = 44$), followed by respiratory disease ($n = 28$), hypertension ($n = 25$), and diabetes ($n = 12$).

It was possible to ascertain the place of death for 152 people: 90 died in hospital, 11 in a nursing or residential home, 19 in a hospice and 32 at home (Table 1). Nineteen per cent of those who died with cancer and 24% who died with cardiorespiratory disease died at home. ($\chi^2 = 0.442$, degrees of freedom [df] = 1, $P = 0.5$).

The drugs prescribed for the palliation of symptoms at the time of death were identified for 151 people. Overall, they were prescribed a median of three (range 0–15) items. Those who died with cancer were being prescribed a median of three (range 0–15) palliative medications compared with two (0–9) drugs for non-malignant disease, (Mann–Whitney $U = 1801$, $P < 0.01$). People who died with cancer were more likely to be prescribed laxatives, antiemetics, opiates, or analgesics, non-steroidal anti-inflammatory drugs, or dexamethasone, and were less likely to be prescribed diuretics (Table 2).

The number of recorded consultations in the 12 months before death are summarised in Table 3. Patients had an average of almost 20 consultations in this period. People with non-malignant disease tended to have more consultations with GPs in each time period except in the final month of life (Table 3). The proportion of people's consultations with the doctor they consulted most frequently ranged from 19–100%. The proportion of consultations with the two most frequently consulted doctors varied between 32% and 100% and, for the three most frequently consulted doctors, the range was 40–100% (Table 4). There was no difference in continuity between people with cancer and non-malignant disease.

Table 3. Consultations in the last year of life.

| Consultations | All recorded consultations | Recorded consultations with general practitioners | | | | <i>P</i> -value ^a |
|------------------------|----------------------------|---|---------------------|-------------------------|--------------------------|------------------------------|
| | Mean (SD [range]) | Overall mean (SD) | Malignant mean (SD) | Non-malignant mean (SD) | Mean difference (95% CI) | |
| Last 12 months of life | 19.9 (16.0 [0–147]) | 16.8 (11.2) | 17.9 (12.1) | 14.4 (8.4) | 3.5 (-0.4 to 7.3) | 0.08 |
| Last 6 months of life | 13.3 (14.1 [0–141]) | 11.8 (10.0) | 12.8 (11.1) | 9.4 (6.2) | 3.4 (0.0 to 6.8) | 0.05 |
| Last 3 months of life | 8.8 (10.7 [0–91]) | 7.8 (7.7) | 8.5 (8.5) | 6.2 (4.9) | 2.3 (-0.3 to 5.0) | 0.09 |
| Last month of life | 4.2 (6.8 [0–49]) | 3.8 (5.1) | 4.1 (5.7) | 2.9 (3.0) | 1.3 (-0.5 to 3.0) | 0.20 |

$n = 154$. SD = standard deviation. ^a χ^2

Table 4. Proportions of consultations with the single doctor, two doctors, and three doctors consulted most frequently by the patient in the last year of life.

| | <i>n</i> ^a | Percentage continuity with <i>n</i> most frequently seen doctor(s) | | |
|---------------------------|-----------------------|--|---------------------------|---------------------------|
| | | 1 doctor mean (range) | 2 doctors mean (range) | 3 doctors mean (range) |
| Overall | 152 | 59.3 (19.2–100) | 79.9 (32.0–100) | 87.3 (40.0–100) |
| Cancer | 106 | 59.8 (19.2–100) | 77.7 (32.0–100) | 87.1 (40.0–100) |
| Cardiorespiratory disease | 46 | 58.0 (23.3–100) | 78.5 (42.3–100) | 87.8 (56.6–100) |

^aTwo people who died with malignant disease had no recorded consultations with their practice in their last year of life.

The practice notes indicated that 49 people who died of cancer and five who died of cardiorespiratory disease were in receipt of palliative care ($\chi^2 = 15.4$, $df = 1$, $P < 0.0001$). It was possible to identify a date for the initiation of palliative care for 42 (37 with cancer and 5 with respiratory disease) people. For people with malignant and cardiorespiratory disease, the respective median (interquartile range, range) of this terminal phase was 16 (5.5–127, 0–328) days and 23 (26–324, 2–401) days.

Discussion

Summary of main findings

These data have allowed us to compare and contrast the care provided in the last year of life to people with malignant and non-malignant cardiorespiratory disease by two general practices. We found that people with malignant disease were more likely to have a terminal phase identified, and were prescribed more drugs for the palliation of symptoms than those with non-malignant disease. In contrast, people who died of malignant or chronic cardiorespiratory disease consulted a similar number of times in their last year of life, experienced similar continuity of care, had a similar number of comorbidities, and were equally likely to die at home.

Strengths and limitations of this study

We chose to conduct the study in practices committed to providing high-quality end-of-life care to people with cancer. This allowed us to compare what could be achieved by primary care teams that have made a commitment to the provision of palliative primary care of cancer with their current end-of-life care of people with chronic cardiorespiratory disease.

We aimed to capture everyone in each practice who had died of either cancer or cardiorespiratory disease, and to compare the care they received in their last 12 months of life. Using cancer morbidity for the relevant areas for all cancers for those aged under 75 years, we expected a total of between 66 and 77 deaths in the 2 years of the study in both practices (Information provided by Trent Cancer Registry, personal communication), and we identified 108. It is likely, therefore, that we identified most, if not all, cancer deaths. Unfortunately, we cannot make an equivalent estimation for the number of expected deaths from cardiorespiratory disease but, because we used the same procedures to identify both groups, we are likely to have identified the majority. We acknowledge that some cases may have been missed because their death was attributed

to, for example, bronchopneumonia or other agonal event rather than chronic cardiorespiratory disease.

We believe the data extraction to have been accurate because of the training of the data extraction staff and validation of their work. This was, however, a review of medical records and the data presented are those that were recorded. Although both practices are teaching and training practices whose records have reached the standards expected of training practices,²⁴ we cannot tell how complete recording is. We did not have the resources to find and review nursing records, and patient-held records were omitted because they were not used by people with cardiorespiratory disease. These considerations imply that the consultation rates and morbidity recorded are more likely to be an underestimate of the totals because the biases that exist are likely to reduce rather than inflate activity and diagnoses. It is unlikely, however, that there is any systematic bias in recording between malignant and chronic cardiorespiratory disease, and that the under-recording has affected both groups similarly.

Both practices are part of a local 'cancer accreditation' scheme in which practices make a commitment to the provision of high-quality multidisciplinary care to people with cancer from diagnosis to the end of life, hold regular interdisciplinary clinical and educational meetings, and audit their care of people with cancer. Although the care of chronic cardiorespiratory disease is not included in this programme, we do not know whether there has been any generalisation of learning about palliative care of malignant disease to non-malignant disease. Although the generalisability of these findings is uncertain, we can say that, even in these practices, there are important differences between the end-of-life care of people with malignant and non-malignant disease.

Comparison with existing literature

Our understanding of the experience of people dying with chronic cardiorespiratory and other non-malignant diseases and how they compare with those with cancer is improving. For example, we know that people with end-stage cardiorespiratory disease have multiple unmet needs and a poorer quality of life arising from interrelated physical and emotional symptoms and social isolation,¹⁰ and restricted access to a palliative care approach either because of limited awareness of practitioners, or because of institutional priorities.^{4,15,19} These studies also emphasise the difficulties practitioners experience in predicting the tra-

jectory of chronic cardiorespiratory disease,^{4,7,8} and the consequent impacts of this upon therapeutic relationships.

A qualitative study by Murray *et al*⁴ comparing people with lung cancer and cardiac failure found that the former had a more predictable illness trajectory and more information about their illness. The lives of those with cardiac failure were dominated by balancing their complex medical regimens, and characterised by frustration, social isolation, and progressive losses. They received fewer health and social services than people with lung cancer, and their care was often poorly coordinated. A prospective comparative survey of people who were terminally ill with heart failure and people who were receiving palliative care (mainly for cancer) reported no differences in the number or severity of symptoms experienced by them or their use of GPs, but found that the latter were more likely to know that they were likely to die.¹⁴ In their prospective survey Anderson *et al*¹⁵ found that people with chronic respiratory disease were less likely than people with lung cancer to be receiving professional support, especially from a district nurse, and had more 'troublesome problems' that were not being addressed. This paper provides important comparative quantitative data about the care provided by general practices to people who have died with cancer and chronic cardiorespiratory disease. Qualitative data from this project are available in the project report.⁸

Clinical implications

These data highlight the challenges of providing care in the last year of life for both categories of patient. They also emphasise the gap in care between these conditions. It is well recognised that people with chronic cardiorespiratory disease experience multiple symptoms including pain and dyspnoea, symptoms experienced by people with malignant disease.^{2,11-15,19} Yet, in this group, people with non-malignant disease were prescribed fewer opiates, potent agents for the relief of these symptoms. Those with chronic cardiorespiratory disease were much less likely to have a terminal phase of their illness identified, which may contribute to a lower level of prescribing, especially as these agents are capable of causing dependency and, because they are respiratory depressants, are also relatively contraindicated in the presence of respiratory failure.

These data illustrate the challenges faced by practices that aim to improve the end-of-life care for those who are dying and may be at a disadvantage with respect to the care they receive — people with chronic cardiorespiratory (and probably other non-malignant) disease. Such people experience distressing symptoms but there are considerable professional and ethical barriers to the initiation of palliative care, including the formal identification of a 'terminal' phase and its unpredictable length.

Research needs

Although we have described differences in the end-of-life care that people with malignant and non-malignant disease received, their comparative needs at the end of life and the extent to which they are met require further study. Ultimately the research priority must be to determine whether it is possible to identify a terminal phase in the care of people with

non-malignant disease, whether initiation of palliative care can be negotiated with people who have these diagnoses, and whether such steps improve the end-of-life care they receive.

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