Appropriate place of death for cancer patients: views of general practitioners and hospital doctors

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SUMMARY

Background. The majority of cancer patients in the United Kingdom die in a National Health Service hospital, a setting that is contrary to the wishes of those patients expressing a preference to die elsewhere, for example at home or in a hospice.

Aim. A study was undertaken to determine clinicians' views of the appropriate place of death for cancer patients and to examine factors leading to patients being admitted to a hospital specialist services unit where they died.

Method. A questionnaire was sent to all general practitioners and hospital doctors who had cared for cancer patients who had died between May 1991 and April 1992 in a single health district. The appropriateness of the place of death, whether the patient was terminally ill, reasons for hospital admission and effect on management had different resources been available were determined.

Results. A total of 1022 deaths attributable to cancer were recorded for patients registered with general practitioners in the study area. Questionnaires were returned by general practitioners for 951 of the deaths (93%); hospital doctors returned questionnaires for 216 out of 268 patients (81%) who had been admitted to hospital under the care of a consultant. For deaths which had occurred at home, in a community hospital, residential/nursing home or Marie Curie hospice, the place of death was considered appropriate by general practitioners in over 92% of cases. For deaths in the hospital specialist services unit the place of death was considered probably or definitely appropriate by general practitioners in 83% of the 212 cases, but not appropriate in 17% of cases (P<0.001 compared with all other settings). Hospital doctors considered 27% of deaths in the unit inappropriate. Significantly fewer cases fulfilled the criteria for terminal illness (death expected and palliative treatment commenced) according to general practitioners among those dying in the specialist services unit compared with deaths elsewhere (P<0.001). The most common main reasons for admission to the specialist services unit were for investigation, because of difficult symptom control (apart from pain) and for curative/active treatment. General practitioners reported that management of between a sixth and a quarter of patients admitted to the specialist services unit would have been affected by the availability of 24-hour

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home cover, community hospital beds and a city-based hospice. Among the group of patients fulfilling the study criteria for terminal illness, the effect of other services on patient management would have been considerably higher. Conclusion. A greater proportion of cases where patients died from cancer in settings other than a specialist services unit were considered appropriate by general practitioners compared with deaths in a specialist services unit. For a considerable minority of patients, death in a specialist services unit was not considered appropriate by the general practitioners or by the hospital doctors. Improvements in local hospice facilities, community hospitals and community support would mean that a substantial proportion of hospital admissions could be avoided and thus cancer patients could die in more appropriate settings.

Keywords: place of death; terminal care; patient choice; doctors' satisfaction.

Introduction

PYING in the appropriate place is of immense importance to many patients and reasons for changes in the place of death have been reviewed.¹ For cancer patients, studies have been carried out to determine patients' wishes.² and those of their carers.⁴ In the studies of patients' wishes, over three quarters of the patients expressing a preference wished to die at home or in a hospice, despite the fact that over half of cancer patients in the United Kingdom die in a National Health Service bed.⁵ In the carers study only just over half of the carers of patients dying in hospital were satisfied with the place of death.⁴

In an attempt to determine why cancer patients die in specialist hospital beds, a study was undertaken of all adult cancer deaths which had occurred over a 12-month period in a single health district, examining the following factors: whether the clinician felt that the place of death was appropriate, the reasons for admission to a hospital specialist services unit; whether criteria for terminal illness were fulfilled; and if the availability of additional resources would have affected patient management.

Method

The study was undertaken in Exeter Health District (population 315 000) which has a hospital specialist services unit (923 beds) with radiotherapy and oncology services, and community hospitals (428 beds) in 10 towns serving the area outside the city of Exeter. Community hospital beds contain general practitioner controlled beds and beds supervised from day to day by general practitioner clinical assistants. General practitioners within the city (population 100 000) and in a few rural areas have no direct access to general practitioner controlled medical beds. At the time of the study there was a Marie Curie hospice situated on the periphery of the health district (17 miles from Exeter) but no hospice in Exeter, no consultant in palliative medicine, or hospital-based symptom control team. A domiciliary hospice service operated in the city and coastal areas offering Macmillan nurse support, social work support and a volunteer network. There was no statutory provision of 24-hour community nursing support.

Over the period May 1991 to April 1992 all cancer deaths in people aged 16 years and over were identified from the death certificate returns from the office and sub-offices of the district registrar of births and deaths. Permission to view all certificates was granted by the office of the registrar general. Cancer deaths were those that included a neoplastic disease on parts 1a, 1b, or 1c of the death certificate (causes leading directly to death). The patient's general practitioner, and where appropriate the consultant, were identified using the certificate and the hospital computer system.

Reply paid envelopes were sent with questionnaires to the general practitioner who had signed the death certificate or the general practitioner with whom the patient was registered if the death occurred in the specialist services unit. They were also sent to the consultant when the death had been in a hospital specialist services bed. Doctors were asked to pass the questionnaire on to the person who had been most involved in the patient's care. In order to test its acceptability the questionnaire was initially sent to a small sample of general practitioners and consultants and any necessary alterations then made. Prior to the study, all general practitioners and consultants had been sent a letter explaining the reason for the study and requesting their cooperation. Follow up of non-respondents was carried out after four weeks by telephone and, where requested, a second questionnaire was sent.

The questionnaire asked for details of the respondent's status: for general practitioners whether they were a principal, locum or trainee, and for hospital doctors whether they were a consultant, senior registrar, registrar, senior house officer or house officer.

To determine whether criteria for terminal illness were fulfilled the following questions were asked: 'Had palliative (that is, non-curative) treatment been started at the time of his/her death?' and 'Did you expect this death to occur when it did?' Patients for whom the clinician answered 'yes' to both of these questions were considered to have had a terminal illness.

The question 'Given the existing resources do you feel with hindsight that this patient died in the most appropriate place?' was posed with the following possible answers: definitely yes, probably yes, do not know, probably no, definitely no.

If the patient had died at the hospital specialist services unit the main reason for admission was requested from the following list: curative/active treatment; investigation; management of pain; other difficult symptom control (apart from pain); social reasons including relatives not coping, respite care, patient living alone, patient's request; medical reasons unrelated to cancer; and other reasons.

The effect of different care options on the management of the patient was assessed by asking if access to a city-based hospice, community hospital beds, a domiciliary hospice nursing service and 24-hour home care (volunteer/nursing services) would have affected the clinician's management. Whether or not the domiciliary hospice service was involved in the care of the patient was also determined.

Finally, the responding clinician was asked if there were any written comments he or she would like to make concerning the management or care of the patient.

The results were coded and entered on to a computer. Statistical significance was tested by chi square analysis and use of the kappa statistic where paired data were available.

Results

Between May 1991 and April 1992 1055 deaths attributable to cancer were recorded, including 33 deaths where the general practitioner practised outside the health district. Of these 33 deaths 24 occurred in the hospital specialist services unit and were referrals for radiotherapy from adjacent health districts. All 33 cases were excluded from the study. Questionnaires were sent

to the general practitioners caring for the 1022 patients and to the consultants caring for the 268 patients admitted under their care by general practitioners in the study area.

There were 186 general practitioners with cases in the study (median five cases, range 1–17) and 34 consultants with cases in the study (median six cases, range 1–27). General practitioners returned questionnaires for 951 cases (93.1%), with 97.9% of responses coming from principals in general practice. Hospital doctors returned questionnaires for 216 cases (80.6%) with 76.4% of responses coming from consultants and the remainder from more junior staff.

The place of death was determined for all 1053 deaths (not known in two cases). A total of 352 deaths occurred at home (33.4%), 292 in the specialist services unit (27.7%), 236 in a community hospital (22.4%), 98 in a Marie Curie hospice (9.3%) and 75 in a nursing home or residential home (7.1%). Access by the general practitioner to the domiciliary hospice service was available in 59.8% of cases and the hospice service was involved in 64.0% of the 569 cases with access (38.3% of the total deaths).

Terminal illness

The number of cases fulfilling and not fulfilling the criteria for terminal illness is shown in Table 1. According to general practitioners between 73% and 80% of patients dying in a place other than the specialist services unit were considered to have fulfilled both criteria for terminal illness and fewer than 5% fulfilled neither criterion. Patients dying in the specialist services unit were significantly less likely to fulfil both criteria compared with patients dying elsewhere ($\chi^2 = 131.2$, 2 degrees of freedom (df), P < 0.001). Hospital doctors' responses indicated that 61% of cases in the specialist services unit fulfilled both criteria for terminal illness. The kappa statistic performed on completed data sets from both groups of clinicians for hospital specialist services unit deaths indicated no significant agreement over and above that expected (agreement occurring in 77% of cases).

Appropriateness of place of death

Clinicians' perceptions of the appropriateness of the place of death of their cancer patients are shown in Table 2. Between

Table 1. Cases fulfilling and not fulfilling criteria for terminal illness according to general practitioners and hospital doctors, by patients' place of death.

	% of ca	Other response	
Place of death	Death expected, palliative f death care started		
General practitioner			
responses ^a Home (n = 328)	75.3	4.0	20.7
Community hospital ($n = 21$		3.7	20.7 17.9
Residential/nursing home	0) /0.4	3.7	17.9
(n=67)	73.1	4.5	22.4
Marie Curie hospice (n = 85) Specialist services unit	80.0	3.5	16.5
(n = 217)	45.2	28.6	26.3
Hospital doctor responses ^b Specialist services unit (n = 200)	61.0	12.0	27.0

n= number of deaths. *Data missing in 36 cases. *Data missing in 16 cases.

Table 2. General practitioners' and hospital doctors' perceptions of the appropriateness of their cancer patients' place of death.

	% of cases where place of death		
Place of death	Appropriate	Not appropriate	
General practitioner responses			
Home (n = 327)	98.5	1.5	
Community hospital ($n = 211$)	97.2	2.8	
Residential/nursing home ($n = 64$) <i>92.2</i>	7.8	
Marie Curie hospice (n = 82)	92.7	7.3	
Specialist services unit ($n = 212$)	83.0	17.0	
Hospital doctor responses ^b Specialist services unit (n = 205)	73.2	26.8	

n= number of deaths. *Data missing in 55 cases. *Data missing in 11 cases.

92% and 98% of deaths in a place other than the specialist services unit were considered by the general practitioners to be definitely or probably appropriate whereas for deaths in the specialist services unit, 83% of deaths were considered by general practitioners definitely or probably appropriate ($\chi^2 = 50.6$, 1df, P<0.001). Hospital doctors considered the hospital specialist services unit to be an inappropriate place of death (definitely or probably) for 27% of cases. The kappa statistic performed on completed data sets from both groups of clinicians for specialist services unit deaths indicated no significant agreement over and above that expected (agreement occurring in 68% of cases).

Further analysis of hospital specialist services unit cases comparing the appropriateness of the place of death with general practitioners' and hospital doctors' expectations of terminal illness is shown in Table 3. There was no significant difference in the general practitioners' perceptions of the appropriateness of place of death among those considered to have had and not to have had a terminal illness, but hospital staff showed a significant difference perceiving those cases with terminal illness to have died in an inappropriate place ($\chi^2 = 8.69$, 2 df, P < 0.05).

Main reason for hospital admission

The main reason for admission to the specialist services unit according to hospital doctors and general practitioners is shown in Table 4. Both general practitioners and hospital doctors considered investigation the most common reason for admission,

Table 3. Hospital specialist services unit patients fulfilling and not fulfilling the criteria for terminal illness, and the appropriateness of their place of death according to general practitioners and hospital doctors.

	% of ca		
Is place of death appro- priate according to:	Death expected, palliative care started	Death not expected, palliative care not started	Other response
General practitioners Yes	(n = 85) 77.6	(n = 54) 90.7	(n = 55) 85.5
No	22.4	9.3	14.4
<i>Hospital doctors</i> ^b Yes No	(n = 122) 67.2 32.8	(n = 23) 91.3 8.7	(n = 48) 83.3 16.7

n = number of patients dying in a specialist services unit who did or did not fulfill the criteria for a terminal illness. *Data missing for 50 cases. *Data missing for 23 cases.

Table 4. Main reason for admission of patients to the specialist services unit, as reported by general practitioners and hospital doctors.

	% of cas	% of cases reported by	
Main reason for admission	GPs (n = 239)	Hospital doctors (n = 211)	hospital doctor agreement
Investigation	39.7	29.4	40 (54.8)
Difficult symptom			
control	19.7	24.2	20 (<i>50.0</i>)
Curative/active treatmen	t <i>15.5</i>	19.9	16 (<i>57.1</i>)
Social reasons	15.1	10.0	12 (44.4)
Management of pain Medical reason unrelate	<i>6.3</i> d	9.5	5 (<i>35.7</i>)
to cancer ^b	3.8	4.7	1 (20.0)

n = number of cases admitted to specialist services unit reported on by clinicians. ^aNot including pain control. ^bFor example, myocardial infarction, deep vein thrombosis.

with difficult symptom control and curative/active treatment the next most common main reasons (accounting for 74% of cases). The degree of agreement between the two groups of clinicians for each case for these three admission reasons was between 50% and 57%. Pain control and management of other symptoms accounted for 26% of admissions according to general practitioners and 34% according to hospital staff. Social reasons for admission (relatives not coping with care, respite care, patient living alone and patient's request) accounted for 15% of cases according to general practitioners and 10% of cases according to hospital staff. Five cases were considered by hospital doctors to be admissions for reasons other than the six reasons listed.

Patient management had other services been available

Clinicians' responses as to whether the availability of different services would have altered management of patients dying in the specialist services unit are shown in Table 5. The availability of community hospital beds and a city-based hospice would have affected the management of around one quarter of general practitioners' cases. The availability of a city-based hospice would have affected the management of over one third of cases by their responsible hospital doctors. Twenty four-hour home cover (nursing or volunteer) would have affected management of around one in six cases according to both hospital doctors and general practitioners. The presence of the domiciliary hospice nursing service (not able to provide 24-hour cover) would have had little effect on those without access.

The data were analysed further according to whether or not the death was expected and palliative treatment started (Table 5). According to general practitioners availability of community hospital beds, a city-based hospice and 24-hour home cover would have affected management in a substantial number of cases fulfilling the criteria for terminal illness (between 26% and 39%). Availability of the listed resources would have affected the management of patients fulfilling neither criteria for terminal illness in 6% of cases or fewer. According to hospital doctors, availability of community hospital beds would have affected management in 29% of cases fulfilling the criteria for terminal illness and availability of a city-based hospice would have affected management in 50% of cases.

Respondents' comments

Comments on each case were invited and those that follow illustrate some of the problems encountered in the management of

Table 5. Proportion of cases dying in the specialist services unit where availability of other services would have affected management according to general practitioners and hospital doctors, and according to whether the cases fulfilled the criteria for terminal illness.

	% of cases where availability of service would have affected management			
	Community hospital beds	City- based hospice	24-hour home cover	Domiciliary hospice nursing service
General practitioners	28.7° (n = 143)	23.1 (n = 216)	17.6 (n = 170)	9.9° (n = 131)
Hospital doctors	19.0° (n = 163)	36.6 ($n = 194$)	16.6 (n = 169)	7.5 ^a (n = 146)
General practitioners considering:				
Death expected, palli- ative care started	<i>38.9</i> (<i>n</i> = 59)	34.5 (n = 87)	<i>26.1</i> (<i>n</i> = 69)	18.8 (n = 48)
Death not expected, palliative care not started	6.3 (n = 32)	5.6 (n = 54)	4.9 (n = 41)	5.6 (n = 36)
Hospital doctors considering:				
Death expected, palli- ative care started	28.7 (n = 87)	50.0 (n = 112)	17.6 (n = 91)	6.6 (n = 76)
Death not expected, palliative care not started	0 (n = 30)	0 (n = 21)	5.0 (n = 20)	0 (n = 20)

n = number of cases where a patient had died. ^aResponse from those clinicians who did not have access to the service.

terminally ill cancer patients in a hospital specialist services unit. The following were written by consultants:

'Died awaiting a geriatric bed. He had been in the Marie Curie hospice, but his wife found travelling too difficult.'

'Classic case of inevitable death that was not ideally managed in the specialist unit.'

'She hated being in hospital.'

The following were written by general practitioners:

'Would have been better in a central hospice but no such beds available and hence died in the specialist services unit.'

'I could have looked after her in a community hospital if one had been available.'

Different approaches to the management of the same patient were apparent in several cases, for example, one general practitioner wrote:

'Transferred from community hospital because of rectal bleeding'

while the consultant wrote:

'Transfer was probably unnecessary.'

Many comments reflected the situation where a patient had been admitted for investigation to aid diagnosis but had deteri-

orated suddenly in hospital. Several comments stated that cancer was a post-mortem diagnosis. A substantial number of comments were made regarding poor communication between the specialist services unit and general practitioner and primary health care team, for example, one general practitioner wrote:

'I still have no idea why or how or when he was admitted nor any details of his death.'

Another general practitioner wrote:

'This lady was admitted to the specialist services unit without my knowledge and more alarmingly I was unaware she had died until I received the questionnaire.'

It was apparent from a number of comments that rapid deterioration of patients admitted for treatment or investigation had occurred and that in these instances it was neither possible nor appropriate to organize a transfer home, to a hospice or a community hospital setting.

Discussion

The response rate from both hospital doctors and general practitioners was high and probably a result of simplifying the questionnaires in response to the pilot study, the letter of explanation preceding the study, and the fact that two of the general practitioner researchers were familiar to the majority of the consultant staff and general practitioners. The data for place of death are in accord with national figures from the hospice information service. The crude death rate was similar to that in preceding years, and the primary type of cancer in broad agreement with national statistics.

The terminally ill patient has been variously defined, ⁷⁻⁹ with an acceptable definition being a patient for whom, following accurate diagnosis, the advent of death is certain and not too far distant and for whom treatment has changed from curative to palliative. ⁷ The current study attempted to define a group of patients for whom, according to the clinician caring for the patient, death was expected and for whom treatment had changed from curative to palliative, and to assess differing management and resource requirements. For patients dying in places other than the hospital specialist services unit the high proportion fulfilling the criteria for terminal illness reflects the perception of appropriate place of death in these settings. In the majority of cases the patients would have been receiving continuing care by the primary health care team and this factor is likely to influence the perceptions of general practitioners.

Patients dying in the specialist services unit were less likely to fulfil the criteria for terminal illness, with the difference between hospital doctor and general practitioner perceptions probably being a reflection of the former group having more frequent access to a firm diagnosis (backed by the main reason for admission to the unit being for investigation) and being more closely associated with the management of the final illness. For the majority of cancer deaths in the specialist services unit (approximately three quarters) the place of death was perceived as appropriate by the two groups of clinicians and would agree with the reasons for admission for curative treatment and investigation. However, in 17% of cases according to general practitioners and in 27% of cases according to hospital doctors the specialist services unit as the place of death was probably or definitely not appropriate, and these figures are a cause for concern. Significantly more of the patients fulfilling the criteria for terminal illness compared with those not fulfilling the criteria were considered by the hospital doctors to have died in an inappropriate setting which would indicate that from the hospital doctors'

point of view the specialist services unit was not an appropriate setting for a substantial proportion of terminally ill patients.

Some explanation as to why some cancer deaths in the specialist services unit were perceived as inappropriate may be found in the reasons for hospital admission, in the responses to the questions on whether or not other resources would have affected patient management, and in the comments made by clinicians. Main reasons for admission to the specialist services unit showed that similar views were held among general practitioners and hospital doctors with investigation, difficult symptom control (apart from pain) and curative treatment being the three most frequently cited. Difficult symptom control and pain control accounted for 26% of admissions according to the general practitioners and for 34% according to hospital staff. These areas of symptom control are part of the specific skills of hospice staff and would indicate that where these problems predominate and the need for investigation and curative treatment is not indicated, admission to a hospice bed or the involvement of a domiciliary hospice team would be more appropriate.

Considering the data on management of patients dying in the specialist services unit, general practitioners and hospital doctors indicated that their management would have been affected in one fifth to one quarter of cases had community hospital beds been available, and in one quarter to one third of cases had a citybased hospice been available. A previous study has indicated that in areas with access to community hospital beds such beds are used as a hospice-type service for patients dying of cancer with a consequent decrease in the number of deaths in specialist services beds, indicating that management can be affected by availability of such resources. 10 Responses to the availability of 24hour home cover indicated that management would have been affected in about one in six cases. Taken with the data on reasons for admission it appears that perhaps a third of patients suffering from cancer were referred to the specialist services unit for reasons of symptom control, lack of adequate home care support and lack of hospice-type beds and that these patients die in an inappropriate setting, according to the clinician caring for the patient. These observations accord with those published by Cartwright¹¹ who concluded that the main shortcomings of a hospital service were inadequate hospice beds and that inadequacies in community services discouraged care in the community.

Comments from clinicians draw attention to situations where management could have been improved (in their opinion) had different facilities been available such as hospice beds in the city, geriatric beds and community hospital beds. The comments referring to poor communication between the specialist services unit and the primary health care team are disturbing and reflect those made by Townsend and colleagues.³ They clearly have profound implications for bereavement counselling and are damaging to hospital doctor-general practitioner relationships.

Despite the study area having above average provision of community hospital beds, 12 a peripherally situated Marie Curie hospice and fewer than the national average of cancer deaths in NHS hospitals,5 death in the specialist services unit was not considered appropriate by hospital doctors in 27% of cases. Availability of facilities such as hospice-type accommodation and improved community support would have affected management in around a quarter to a third of cases. In the national context, this could have widespread implications with a substantial proportion of admissions of cancer patients to hospital specialist services units being avoided, thus cancer patients could choose to die in more appropriate settings.

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