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Specialist palliative care in nonmalignant disease

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Key words: palliative care; hospices; health care needs and demands; health services accessibility; noncancer (non-MeSH); terminal care

The objective of this study was to investigate how many patients who die from causes other than cancer might benefit from specialist palliative care.

This was achieved by secondary analysis of data from the Regional Study of Care for the Dying, a retrospective national population-based interview survey. The investigation involved 20 self-selected English health districts, nationally representative in terms of social deprivation and most aspects of health services provision. A total of 3696 patients were randomly selected from death registrations in the last quarter of 1990; an interview concerning the patient was completed 10 months after the death by bereaved family, friends or officials.

The results show that a third (243/720) of cancer patients who were admitted to hospices or had domiciliary palliative care scored at or above the median on three measures of reported symptom experience in the last year of life. That is the number of symptoms (eight or more), the number of distressing symptoms (three or more) and the number of symptoms lasting more than six months (three or more). A total of 269 out of 1605 noncancer patients (16.8%) fulfilled these criteria. On this basis, it is estimated that 71 744 people who die from nonmalignant disease in England and Wales each year may require specialist palliative care. An increase of at least 79% in caseload would, therefore, be expected if specialist palliative care services were made fully available to noncancer patients. This is a conservative estimate, as non-cancer patients were matched to only one-third of cancer patients who had specialist palliative care.

It is concluded that clinicians and patient groups caring for patients with advanced nonmalignant disease must work together with specialist palliative care services and with health commissioners to develop, fund and evaluate appropriate, cost-effective services which meet patient and family needs for symptom control and psychosocial support.

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L'objectif de cette étude était étudier combien de patients qui meurent des causes autre que le cancer peuvent profiter des soins palliatifs spécials. Ceci était atteint par l'analyse secondaire des données de l'étude régionale de soins pour les mourants, une enquete nationale rétrospective des interviews axée sur la population. Cette étude a entraîné 20 régions de la santé anglaises autosélectionnées, répresentatives de tout le pays en termes de la privation sociale et la plupart d'aspects de la provision de services de la santé. Un total de 3696 patients a été sélectionné au hasard des enregistrements de mort pendant le dernier quart de 1990, une interview ce qui concerne le patient a été terminée 10 mois après le mort par la famille endeuillée, les amis ou les fonctionnaires.

Les résultats ont montré qu'un tiers (243/720) de patients atteints d'un cancer qui ont été admis en hospices ou qui ont eu les soins palliatifs à la domicile ont marqué à ou au dessus la moyenne de trois mesures d'expériences des symptômes rapportées dans la dernière année de vie. Çela est le nombre de symptômes (huit ou plus), le nombre de symptômes angoissants (trois ou plus) et le nombre de symptômes qui durent plus de six mois (trois ou plus). Un total de 269 des 1605 patients non-cancéreux (16.8%) ont satisfait ces critères. Dans ces conditions, il est estimé que 71 744 personnes qui meurent à cause des maladies non-malignes en Angleterre et le pays de Galles chaque année peuvent avoir besoin de soins palliatifs spécials. Une augmentation de 79% au moins dans le charge de cas serait, dont, être escompté si on faisait des services de soins palliatifs spécials entièrement disponible aux patients non-cancéreux. Ceci est une évaluation modeste parce que les patients non-cancéreux étaient égales à un tiers seulement de patients atteints d'un cancer qui ont eu les soins palliatifs spécials.

Il était conclus que les cliniciens et les groupes qui soigner les patients avec la maladie non-maligne en stade avancé doivent travailler ensemble avec les services de soins palliatifs spécials et avec les commissaires de la santé pour développer payer et évaluer les services justes et rentables qui répondent aux besoins du patient et la famille pour le contrôle de symptômes et le soutien psychosocial.

Introduction

The rapid growth of specialist palliative care has led to improved care for the minority in direct receipt of these services[1] and, as palliative care principles have permeated into the mainstream of cancer care, for the majority who do not receive these services.[2] However, most people do not die from cancer. People who die from other diseases may also need improved symptom control, better nursing care, and more open communication about death and dying.[3–5] In 1992, an expert report recommended the provision of palliative care services to all patients who need them, regardless of diagnosis;[6] this was reinforced in a UK National Health Service (NHS) Executive Letter on palliative care.[7] However, fewer than 4% of patients admitted for the first time to a hospice or specialist palliative care unit in 1994–95 had nonmalignant disease,[8] despite most of these services reporting that they would accept referrals for these patients.[8]

Little is known about the needs of people who die from nonmalignant diseases, the adequacy of existing services, or, indeed, the effectiveness of specialist palliative care for these patients. Better information is needed if palliative care services for noncancer patients are to develop in an appropriate and cost-effective way. In particular, the question of which noncancer patients might benefit from specialist palliative care needs to be addressed in order to target funding and services.

In this paper we have used data from the Regional Study of Care for the Dying (the RSCD), a national population-based survey,[9] to investigate what proportion of people who die from nonmalignant disease may benefit from specialist palliative care, to describe their characteristics, and to examine how well existing services are meeting their needs.

The RSCD was a retrospective study in which bereaved relatives and friends were interviewed, 10 months after the death, about the last months of a randomly selected sample of people. The validity of retrospective accounts of patients' symptoms has been questioned, especially for pain;[10–12] these results are, therefore, hypothesis-generating rather than definitive. However, bereaved respondents' accounts have their own validity as it is these that live on. In addition, many terminally ill patients are too ill to participate in research[13,14] and/or are not recruited for prospective palliative care studies because they continue in active treatment. In contrast, the RSCD sampled at random from death certificates and the study, therefore, provides information on a complete population. Which noncancer patients may benefit from specialist palliative care has not been addressed empirically before, and, as the Department of Health (DoH) inspired drive towards equitable palliative care provision is likely to continue,[15] the results presented here are an important first step towards providing an evidence-base for service developments in this field.

Methods

The Regional Study of Care for the Dying

Twenty English health districts participated in the RSCD. The districts were self-selected, but were nationally representative in terms of social deprivation, and in most aspects of health service provision.[16] Within each district, 270 deaths of district residents aged 16 or over in the last quarter of 1990 were sampled randomly from death certificates. Cancer deaths were sampled disproportionately and made up 54% of the sample. In total, 5375 deaths were sampled, 2915 of whom died from cancer.

A letter was sent to the deceased's address, as shown on the death certificate, informing the recipient about the study. Interviewers then contacted the address to identify the person who could tell them most about the deceased's last year of life, and this person was then interviewed using an adapted version of the schedule used in a previous national survey.[17] Topics covered included use of and satisfaction with services in the last year of life, symptoms and symptom control, communication with health professionals, and the respondent's experience of caring, bereavement and bereavement care. The median time between death and interview was 44 weeks (interquartile range, 39.6–49.7). A 69% response rate was achieved, giving 3696 interviews, 1622 of which were for noncancer deaths. The RSCD methods are described in detail elsewhere.[9,16]

Selection criteria

Noncancer patients who had similar symptom experience to cancer patients who had specialist palliative care were selected. Respondents named hospitals and hospices to which the deceased was admitted in the last year of life. Those included in the *1990 Directory of hospice services* were classified as hospices.[18] Hospice inpatient care was received by 342 cancer patients, and 574 received care at home from specialist palliative care nurses. (There was some overlap between the groups.) Neither symptom severity or level of dependence differed significantly between the two groups, which were therefore combined ($n = 720$).

Respondents were asked whether the deceased had had any of 16 symptoms (Table 3) in the last year of life, and, if so, whether they thought they had found it very, fairly or not very distressing, and how long they had had it for. The median number of symptoms reported to have been experienced by cancer patients who had received specialist palliative care was eight (range 0–16); the median number of very distressing symptoms was three (0–16), and the median number of symptoms which lasted six months or more was again three (0–14). A third (243/720) of the cancer patients scored at or above the median score on all three measures of symptom experience. Noncancer patients were selected if they fulfilled the same criteria.

Statistical analysis

Pearson's chi-square test was used to detect statistically significant differences on categorical data between groups. Logistic regression analyses were used to control for the effects of group differences in the relationship of respondent to patient. The results of these analyses are only reported when controlling for these variables reduced the significance level of the results found to be significant in bivariate analysis to below the 95% probability level.

Results

Using the selection criteria based on symptom experience, 269 noncancer patients were selected, accounting for 16.8% of the total noncancer sample. Half had died from a circulatory disease (53.5%), and nearly a quarter from respiratory disease (20.8%) (Table 1). These data were combined with data on the number of deaths from each cause in England and Wales in 1995[19] to estimate the number of people each year who have severe symptoms in their last year comparable with that of the top third of cancer patients who get specialist palliative care in an inpatient hospice or from a specialist palliative care nurse (Table 1). The results suggest that 71 774 people who die from nonmalignant disease in England and Wales each year experience severe symptom distress, more than 21 000 of whom die from respiratory disease, and more than 34 000 of whom die from circulatory disease.

Patient characteristics

Selected noncancer patients were more likely than selected cancer patients to be aged 85 years or over at death, to have lived alone, to have lived in a nursing or residential home at some time in the last year of life, and to have died in a hospital (Table 2). They were less likely to have died at home and none had died in a hospice. They were less likely to have needed help with activities of daily living in the last year of life and, if they needed help, needed it with fewer activities. They were, however, more likely to have needed help with at least one activity of daily living for more than one year.

Symptoms and symptom control

According to the respondents' reports, dry mouth, loss of appetite, difficulty swallowing, nausea/vomiting, constipation, and bedsores were more common in both the last year and last week of life of the selected cancer patients than in the selected noncancer patients (Table 3). Dyspnoea and urinary incontinence were more common in the latter group during both periods, and they were more likely to be reported to have had pain and/or a persistent cough in the last week of life. Selected cancer patients were more likely to be reported to have found four symptoms (dry mouth, loss of appetite, nausea/vomiting, bedsores) very distressing. All but three of the symptoms (dyspnoea, persistent cough and loss of appetite) were reported to have been more long-lasting in the selected noncancer patients. Symptom control by general practitioners (GPs) and hospital doctors for pain, dyspnoea, constipation or nausea/vomiting did not differ significantly between the groups (Table 4).

Information and communication

Two-thirds (64%) of respondents for selected cancer patients were dissatisfied with the information they had received about the patients' medical condition, compared with half (48%) of respondents for selected noncancer patients (Table 5). They were more likely to believe that the patient had definitely known that they were dying (69% versus 39%), and were also more likely to have known this themselves. A third of those who knew had worked it out for themselves, compared with four-fifths of selected noncancer patients.

Choice about place of death

Selected noncancer patients were more likely than selected cancer patients to have died alone (Table 5) and both they and their families were less likely to be reported to have had any choice about place of death.

Discussion

Little is known about what distinguishes cancer patients who get specialist palliative care from those who do not, or how this varies between different types of specialist palliative care service (e.g. inpatient hospice, domiciliary or hospital palliative care team, or day hospice).[20,21] Although symptom control is central to palliative care, symptoms alone were not powerful predictors of hospice

Table 1 Main cause of death of noncancer patients selected because they matched, in terms of symptom severity, the top third of cancer patients who received specialist palliative care; and the projected number of cases per annum with those levels of symptoms severity

Cause of death[a]	Number of cases selected (number of cases in total sample)	Proportion of cases selected in each category (95% CI)	Percentage of selected cases with cause of death	Expected number of cases[b]	Expected cases/ 1 000 000[c]
Infectious and parasitic diseases	3 (12)	0.25 (0.09–0.53)	1.1	921	35
Endocrine, metabolic and immune disorders	8 (46)	0.17 (0.09–0.30)	3.0	1372	52
Diseases of blood and blood forming organs	4(8)	0.5 (0.22–0.78)	1.5	965	36
Mental disorders	12 (56)	0.21 (0.12–0.33)	4.5	1958	70
Diseases of the nervous system	10 (52)	0.19 (0.11–0.32)	3.7	1867	70
Diseases of the circulatory system	144 (1008)	0.14 (0.12–0.16)	53.5	34804	1296
Diseases of the respiratory system	56 (242)	0.23 (0.18–0.29)	20.8	21090	769
Diseases of the digestive system	13 (61)	0.21 (0.13–0.33)	4.8	4146	154
Diseases of the genitourinary system	4 (18)	0.22 (0.09–0.45)	1.5	1580	58
Diseases of the musculoskeletal system	9 (25)	0.36 (0.20–0.55)	3.3	1313	48
Congenital anomalies	2 (9)	0.22 (0.06–0.55)	0.7	286	11
Ill-defined symptoms	3 (27)	0.11 (0.04–0.28)	1.1	1087	37
Injury and poisoning	1 (41)	0.02 (0.00–0.12)	0.4	385	15
Total	269 (1605)		100%	71774	

[a] Classified using OPCS rules for assigning main cause of death, using International Classification of Disease.
[b] Expected number of cases is equal to the number of deaths in England and Wales in 1995 times the percentage of selected cases in each category.
[c] Expected cases per million population is calculated by multiplying the death rates per million population in England and Wales in 1995 by the percentage of selected cases in each diagnosis.

admission within the RSCD, as dependency, age and type of cancer also played a significant role.[20] However, noncancer patients are on average older than cancer patients, and they also have different patterns of dependency.[22] To exclude patients from specialist palliative care on the basis of age and dependency would preclude an equitable use of specialist palliative care resources. The criteria for selecting patients who died from causes other than cancer and might benefit from specialist palliative care were, therefore, restricted to symptoms.

Our results reflect bereaved respondents' views of symptom severity and control. We do not know how precisely these relate to the patients' own views, or to those of health professionals. The RSCD did not collect any information from medical records; we therefore do not know what caused each symptom, nor can we make judgements as to how readily

Table 2 Comparing selected noncancer (n = 265) and selected cancer patients who fitted the selection criteria (n = 243) in terms of patient characteristics, place of death, and relationship between deceased and patient

	Noncancer % (n)	Cancer % (n)	χ^2	P
Sex				
Male	51 (265)	53 (243)	0.23	0.6
Female	49	47		
Age (years)				
Under 65	11 (264)	34 (243)	82.6	<0.0001
65–74	22	38		
75–84	45	21		
85 or more	22	7		
Marital status				
Married	36 (262)	57 (242)	26.7	<0.000
Single	11	7		
Widowed	50	31		
Divorced/separated	3	5		
Place of death[a]				
Home	17 (262)	40 (243)		
Hospital	68	23		
Hospice	0	35		
Residential/nursing home	13	2		
Other	1	0		
Lived in nursing or residential home sometime in last 12 months	32(256)	5 (243)	59.8	<0.001
Relationship to respondent				
Spouse	25 (265)	49 (243)	39.5	<0.001
Close relative	47	38		
Other relative	11	8		
Friend/neighbour	7	3		
Official	9	2		
Number of self-care activities help needed with				
None	11 (237)	7 (242)	27.1	<0.0001
1–2	22	7		
3–4	13	14		
5–6	22	27		
All 7	32	45		
Number of activities help needed for more than a year				
None	33 (235)	68 (240)	69.1	<0.0001
1–2	30	22		
3 or more	37	10		

[a] χ^2 could not be calculated due to empty cells.

treatable the symptom was, or whether it was likely to be outside the management skills of attending GPs and hospital doctors. As indicated earlier, these results are hypothesis-generating rather than definitive and further research is needed.

One in six noncancer patients had similar levels of reported symptom 'load' as the most severely affected third of cancer patients who had specialist palliative care. Although some symptoms associated with terminal cancer were less common in selected noncancer patients, others, including pain and dyspnoea, were neither less common nor, according to respondents' accounts, less severe, and were more likely to have been long-lasting. Reported symptom control was similar in hospital and in primary care. Pain was reportedly more common in noncancer patients in the last week of life, although overall prevalence in the last year did not differ between the

Table 3 Reported symptom prevalence, duration and severity in the last year of life

	Percentage reported to have had symptom in the last year of life		Percentage reported to have had symptom in the last week of life		Percentage reported to have found symptom very distressing[b]		Percentage reported to have had symptom for more than six months[c]	
	Selected cancer % (*n*)[a]	Selected non-cancer % (*n*)[a]	Selected cancer % (*n*)[a]	Selected non-cancer % (*n*)[a]	Selected cancer % (*n*)[a]	Selected non-cancer % (*n*)[a]	Selected cancer % (*n*)[a]	Selected non-cancer % (*n*)[a]
Pain	96 (243)	94 (261)	67 (221)	77 (225)*	71 (227)	72 (242)	79 (228)	86 (241)**
Dyspnoea	73 (241)	81 (264)*	55 (126)	75 (253)***	63 (168)	64 (210)	65 (175)	72 (214)
Persistent cough	41 (241)	47 (265)	26 (237)	37 (249)**	50 (97)	42 (123)	83 (99)	88 (122)
Dry mouth	86 (235)	73 (257)***	74 (210)	63 (214)	43 (193)	34 (175)***	46 (199)	68 (183)***
Loss of appetite	92 (243)	77 (264)***	79 (228)	70 (239)**	33 (210)	21 (193)**	59 (223)	65 (200)
Difficulty swallowing	63 (238)	48 (252)***	51 (243)	41 (223)*	63 (143)	53 (117)	37 (148)	56 (120)***
Nausea/vomiting	82 (240)	56 (257)***	46 (217)	33 (232)***	66 (127)	50 (71)**	56 (194)	63 (141)***
Constipation	84 (234)	69 (254)***	55 (195)	44 (195)*	65 (191)	69 (173)	59 (193)	85 (175)***
Bedsores	50 (240)	38 (251)**	44 (232)	30 (242)**	75 (107)	58 (88)*	13 (118)	31 (94)***
Urinary incontinence	55 (242)	65 (262)*	47 (229)	59 (248)**	76 (123)	72 (161)	34 (130)	62 (169)***
Faecal incontinence	46 (240)	53 (258)	35 (222)	42 (238)	89 (101)	82 (125)	30 (108)	56 (133)***
Unpleasant smell	46 (239)	38 (262)	39 (233)	30 (247)*	41 (80)	31 (82)	29 (109)	61 (97)***
Mental confusion	62 (242)	61 (263)	47 (227)	50 (249)	42 (133)	44 (147)	22 (148)	62 (161)***
Sleeplessness	81 (239)	81 (258)	43 (211)	54 (221)*	44 (186)	45 (205)	76 (185)	90 (208)***
Low mood	90 (239)	95 (262)*	61 (217)	54 (221)***	67 (204)	73 (242)	69 (213)	89 (246)***
Anxiety/nervousness	52 (241)	60 (260)	30 (228)	42 (235)**	50 (123)	59 (146)	82 (124)	93 (155)***

[a] Denominator.

[b] P-value derived from χ^2 from 2 × 3 contingency table (group × distress (very, fairly,not)).

[c] P-value derived from χ^2 from 2 × 3 contingency table (group × duration < 1 month, 1–6 months, 6+ months).

*P < 0.005; **P < 0.01; ***P < 0.001.

Table 4 Symptom control by general practitioners and hospital doctors

	Symptom control by general practitioners				Symptom control by hospital doctors			
	Selected noncancer		Selected cancer		Selected noncancer		Selected cancer	
	%	(*n*)	%	(*n*)	%	(*n*)	%	(*n*)
Treatment removed pain								
Completely	8	(182)	12	(202)	14	(130)	16	(153)
Completely some of the time	37		40		41		48	
Partially	45		42		35		33	
Not at all	11		6		10		3	
Treatment relieved breathlessness								
A lot	28	(118)	29	(79)	32	(115)	38	(73)
Some	37		33		37		32	
A little/not at all	35		38		32		30	
Treatment relieved constipation								
A lot	30	(103)	26	(151)	28	(50)	28	(64)
Some	42		36		48		38	
A little/not at all	28		38		34		34	
Treatment relieved nausea/vomiting								
A lot	26	(61)	23	(193)	33	(42)	19	(72)
Some	36		41		31		54	
A little/not at all	38		36		36		27	

groups, suggesting that good pain control had been achieved by this stage for the cancer patients, possibly as a consequence of the specialist care they received; the results for dyspnoea are suggestive of the same effect. Selected noncancer patients may have been as much in need of specialist help with symptom control as those cancer patients who did indeed have specialist palliative care.

Over half of the noncancer patients were thought to have known that they were likely to die, but most of these were believed to have worked it out for themselves rather than being told by a health professional. More respondents than patients were believed to have known the prognosis, suggesting a situation akin to that in cancer in the past whereby patients were 'protected' from the knowledge of their impending death, a situation now acknowledged to be both inappropriate and unethical.[23] It is more difficult to judge prognosis in many nonmalignant conditions than in cancer, and for many patients it may have been impossible for health professionals to have given accurate information about their prognosis.[24] However, our data raise the possibility that some patients correctly suspected that they were not going to get better and may have welcomed the opportunity to discuss the possibility that they were dying, but that their doctors were unwilling to discuss this until they were able to predict the patient's life expectancy with a reasonable degree of accuracy; a point unlikely to be reached for many noncancer patients.[24] At least some noncancer patients might, therefore, benefit from open communication about death and dying, and from help to adjust to their prognosis. Further work is needed to explore how much information about their prognosis noncancer patients would like to be given, and to investigate the practicalities of providing this information, given the difficulties of estimating prognosis in nonmalignant disease.

Respondents for selected noncancer patients were less likely than respondents for selected cancer patients to report that the patient had had enough choice about their treatment whilst in the hospital they died in or (if they died elsewhere) where they had spent the most time in their last year of life. They were also less likely to feel that the deceased had had enough choice about the place of death, and that the family had had enough choice about this. More noncancer patients had died alone, contrary to the value attached to 'accompanied dying'.[25] Further studies are needed to identify which aspects of care the respondents and patients would have liked to have had more choice about and the feasibility of offering choice in these areas, given the difficulty in making accurate prognostic judgements. Nevertheless, these results suggest that at

Table 5 Respondents' satisfaction with information received in the last year of life, communication about death and dying, and choice regarding place of death

	Selected noncancer (%)	Selected cancer (%)	χ^2	P
Respondent was unable to get all the information they wanted about deceased's medical conditions, when they wanted it	48 (262)	64 (242)	12.9	<0.001
Deceased knew they were likely to die?				
Yes, certainly	39 (260)	69 (243)	54.3	<0.001
Yes, probably	25	17		
Probably not	12	5		
No, definitely	15	3		
Unable to say	9	6		
Who had told deceased (if they knew certainly or probably)				
None (worked it out for themselves)	81 (166)	31 (209)	105.5	<0.001
General practitioner	3	9		
Hospital doctor	5	40		
Other health professional	1	7		
Respondent	2	4		
Unable to say	8	8		
How long deceased knew before death				
Less than one week	25 (139)	9 (202)	62.9	<0.001
One week, less than one month	21	17		
One month, less than three months	15	24		
Three months, less than six months	11	21		
Six months or more	28	29		
Respondent knew deceased was likely to die				
Knew	59 (258)	89 (242)	62.9	<0.0001
Half knew	19	8		
Did not know	23	3		
Who had told respondent (if knew)				
None (worked it out for themselves)	44 (151)	17 (216)	35.0	<0.0001
General practitioner	14	20		
Hospital doctor	29	39		
Other health professional	9	11		
Deceased	3	9		
Relative/friend	1	5		
How long respondent knew before death				
Less than one week	24 (150)	5 (215)	45.2	<0.0001
One week, less than one month	15	11		
One month, less than three months	9	24		
Three months, less than six months	11	25		
Six months or more	40	35		
Respondent would have liked to know prognosis, if did not	39 (56)	38 (8)	0.009	0.9
Deceased alone at time of death				
Yes	34 (264)	12 (243)	34.6	<0.0001
Deceased had enough choice about place of death				
Yes	33 (258)	65 (238)	56.8	<0.0001
No	43	18		
Not sure	5	4		
Other	8	6		
Too ill	11	5		
Family had enough choice about place of death				
Yes	51 (257)	75 (240)	31.4	<0.0001
No	38	18		
Not sure	3	3		
Other	7	4		

least some noncancer patients and their families would welcome the emphasis on autonomy and choice which is so central to the philosophy underpinning specialist palliative care.

In summary, these results suggest that the selected noncancer patients and their families were as much in need of the expertise of specialist palliative care services in symptom control, open communication about death and dying and in encouraging patient and family autonomy as the selected cancer patients, who had by definition been in receipt of these services. These results suggest the current position, whereby very few noncancer patients receive specialist palliative care, is inequitable and unsustainable.

In order to provide information at the population level on the impact of providing specialist palliative care services to noncancer patients, the number of noncancer cases in England and Wales expected to benefit from specialist palliative care services was estimated (Table 1). The expected number of cases was 71 774, 16.8% of all noncancer deaths in England and Wales. Patients with cardiovascular or respiratory diseases make up the bulk of these cases. In 1994–95, 28 000 cancer patients died in a hospice, and 63 000 died whilst receiving domiciliary palliative care, a total of 91 000.[8] Based on these figures, an increase of 79% in the caseload of specialist palliative care services is indicated if these services are made fully available to noncancer patients with severe symptoms. This may be an underestimation as the noncancer patients in RSCD were matched to the top third (in terms of symptom severity) of cancer patients who got specialist palliative care. The number of noncancer patients needing this care may, therefore, be three times as high, that is 215 322, representing half of noncancer deaths in England and Wales. Not all these patients would require inpatient hospice care, or ongoing involvement from a domiciliary or hospital palliative care team and, for many, consultation, advice and support for the patient's GP or hospital physician from a specialist palliative care team member may suffice.[26] Nevertheless, expansion on anything like the scale suggested by our results is clearly unlikely in the current financial climate.

Answering the question of how to meet the palliative care needs of people who die from causes other than cancer will require the qualities of imagination, innovation and dedication which have characterized the hospice movement over the past 30 years; to fail to do so will truly leave it open to the charge of providing deluxe dying for a few whilst ignoring the needs of the majority.[27] However, this is not just an issue for specialist palliative care. The debate about the provision of services to these patients should be opened up to include clinicians and patient groups currently caring for these patients, as well as health service commissioners. These bodies will have important insights into the needs of these patients, input in the management of some of their problems, and (perhaps) funding to enable the development and evaluation of innovative services. The answer to the question of whether cancer patients are alone in needing better symptom control, open communication about death and dying, psychological support and support to families and friends is now clear; the question of how best to address these needs in noncancer patients who die remains to be answered.

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References

1 Higginson IJ. Palliative care: a review of past changes and future trends. *J Public Health Med* 1993; **15**: 3–8.
2 Parkes CM, Parkes J. 'Hospice' versus 'hospital' care – re-evaluation after 10 years as seen by surviving spouses. *Postgrad Med J* 1984; **60**: 120–24.
3 Addington-Hall JM, Lay M, Altmann D, McCarthy M. Symptom control, communication with health professionals and hospital care of stroke patients in the last year of life, as reported by surviving family, friends and carers. *Stroke* 1995; **26**: 2242–48.
4 McCarthy M, Lay M, Addington-Hall JM. Dying from heart disease. *J R Coll Physicians Lond* 1996; **30**: 325–28.
5 Lynn J, Teno JM, Phillips RS *et al*. Perceptions by family members of the dying experience of older and seriously ill patients. *Ann Intern Med* 1997; **126**: 97–106.

6 Standing Medical Advisory Committee, Standing Nursing and Midwifery Advisory Committee. *The principles and provision of palliative care.* London: Standing Medical Advisory Committee and Standing Nurse and Midwifery Advisory Committee, 1992.
7 NHS Executive. *A policy framework for commissioning cancer services: palliative care services.* 1996: London: NHS Executive: EL(96)85.
8 Eve A, Smith AM, Tebbit P. Hospice and palliative care in the UK 1994–95, including a summary of trends 1990–95. *Palliat Med* 1997; **11**: 31–43.
9 Addington-Hall JM, McCarthy M. The Regional Study of Care for the Dying: methods and sample characteristics. *Palliat Med* 1995; **9**: 27–35.
10 Hinton J. How reliable are relatives' retrospective reports of terminal illness? Patients and relatives' accounts compared. *Soc Sci Med* 1996; **43**: 1229–36.
11 Higginson IJ, Priest P, McCarthy M. Are bereaved family members a valid proxy for a patient's assessment of dying? *Soc Sci Med* 1994; **38**: 553–57.
12 Field D, Douglas C, Jagger C, Dand P. Terminal illness: views of patients and their lay carers. *Palliat Med* 1995; **9**: 45–54.
13 Addington-Hall JM, MacDonald LD, Anderson HR *et al*. Randomised controlled trial of co-ordinating care for terminally ill cancer patients. *Br Med J* 1992; **305**: 1317–22.
14 McWhinney IR, Bass MJ, Donner A. Evaluation of a palliative care service: problems and pitfalls. *Br Med J* 1994; **309**: 1340–42.
15 Addington-Hall JM. *Reaching out. Report of the joint NCHSPCS and Scottish partnership agency working party on palliative care for patients with non-malignant disease.* London: National Council for Hospice and Specialist Palliative Care Services, 1997.
16 Addington-Hall JM, McCarthy M. Can national surveys be funded successfully from local NHS resources? Evidence from the Regional Study of Care for the Dying. *J Public Health Med* 1995; **17**: 161–63.
17 Seale C, Cartwright A. *The year before death.* Aldershot: Avebury, 1994.
18 St Christopher's Hospice Information Service. *1990 Directory of hospice services in the UK and Republic of Ireland.* Sydenham, London: St Christopher's Hospice Information Service, 1990.
19 Office of National Statistics. *Mortality statistics general.* London: Her Majesty's Stationary Office, DH2 no. 22, 1997.
20 Addington-Hall JM, Altmann D, McCarthy M. Who gets hospice in-patient care? *Soc Sci Med* 1998; **46**: 1011–16.
21 Hunt R, McCaul K. A population-based study of the coverage of cancer patients by hospice services. *Palliat Med* 1996; **10**: 5–12.
22 Addington-Hall JM, Altmann D, McCarthy M. Variations in age in symptoms and dependency levels experienced by people in the last year of life, as reported by surviving family, friends and officials. *Age Aging* 1998; **27**: 129–36.
23 Buckman R. Talking to patients about cancer. *Br Med J* 1996; **313**: 699–700.
24 Lynn J, Harrell F Jr, Cohn F, Wagner D, Connors AF Jr. Prognoses of seriously ill hospitalized patients on the days before death: implications for patient care and public policy. *New Horiz* 1997; **5**: 56–61.
25 Seale C. Dying alone. *Sociol Health Illness* 1995; **17**: 376–92.
26 George R, Sykes J. Beyond cancer? In: Clark D, Ahmedzai S, Hockley J eds. *New themes in palliative care*. Buckingham: Open University Press, 1997.
27 Douglas C. For all the saints. *Br Med J* 1992; **304**: 479.