

Terminal care in a semi-rural area

E B HERD

SUMMARY. In six months 157 patients died of malignant disease in West Cumbria, a semi-rural area, following a period of terminal care exceeding a week. A total of 53% of patients died at home compared with 24–41% in studies in metropolitan areas. In addition, over one-third of patients who died in hospital were in for a week or less. Patients living further from hospital were more likely to be cared for at home to the end of their illness. The emotional strain of home care was the commonest problem for the lay carer (74%). The commonest reasons for hospital admission were problems in providing care: in 22% of admissions there was no lay carer and in 45% the lay carer became unable to continue to give care. Nearly half the patients dying in hospital were in acute wards, frequently criticized by nurses and relatives as being unsuitable for dying patients.

Despite the high degree of satisfaction expressed for the care provided in all settings, there was evidence of much avoidable suffering. A need for expert advice on palliative care was revealed.

Introduction

PREVIOUS field studies of terminal care have been based on cities,¹⁻⁷ often in relation to hospices. This study deals with a district with a small scattered population, without hospice provision. West Cumbria comprises the coastal strip west of the Lake District. The population of 136 000 live in small towns (maximum population 28 000) and villages with a small number in isolated hamlets and farms in an area 40 miles long and three to 12 miles wide. A six month study of terminal care in this health authority district was undertaken. This paper compares the findings in a rural area with those in urban areas. The problems met by carers, nurses and doctors are presented and their views of the quality of care compared.

Method

For six months from mid-April 1987 death certificates were examined weekly and an initial study group was drawn up of cases in which the primary cause of death appeared to be malignant disease, the patient was over 20 years of age and the patient's home address was in West Cumbria.

The terminal care period was defined as the interval between the point when palliative rather than curative treatment was indicated and the time of death. Cases with a terminal care period of less than a week were excluded.

Interviewers visited the carers. Up to three sets of questionnaires were completed for each patient; one by the doctor and nurse most involved during the last two weeks of life and one by the closest lay carer. The doctors and nurses were interviewed within two weeks of the death and the lay carer within six to eight weeks.

The interviewers were all nurses experienced in community work. They were selected for their ability to deal with the bereaved with sympathy and understanding. The interviewers encouraged all respondents, in particular the lay carers, to talk freely about their experiences.

E B Herd, MRCP, general practitioner, Cockermouth, Cumbria.

© British Journal of General Practice, 1990, 40, 248-251.

Results

Place of death

A total of 157 consecutive adult deaths which fitted the criteria were examined: 90 (57%) men and 67 women. The average age at death was 67 years. Below the age of 70 years more deaths occurred at home while above this age more occurred in hospital (Figure 1).

Eighty three patients died at home: 49 (59%) men, 34 women. The terminal care period lasted between a week and a month in 20% of patients, between one and three months in 41% and more than three months in 39%. The marital status showed a surprising pattern of marital stability: 73% were married, 20% widowed and 7% single, none divorced or separated. Two patients died alone. The chief carer was present at death in 52 out of 59 cases (88%), often with another relative or the nurse.

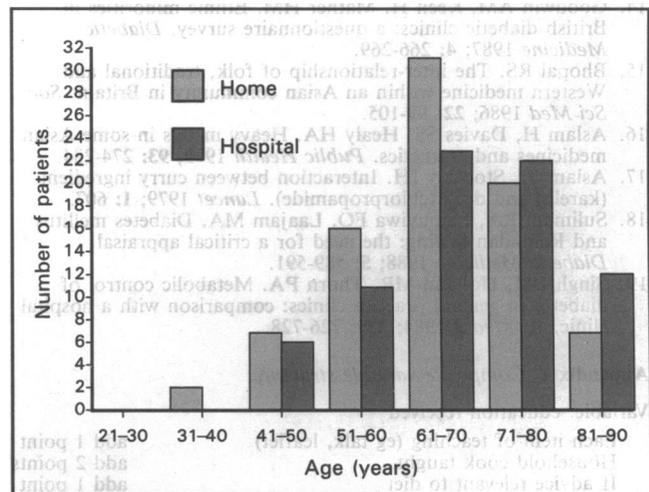


Figure 1. Place of death by age for 157 patients.

Seventy four patients died in hospital: 41 (55%) men, 33 women. The hospitals were a district general hospital without radiotherapy, three cottage hospitals with general practitioner beds and a former acute hospital with general practitioner beds. Within the district general hospital 35 patients were cared for in one of the acute wards (surgical, 18; geriatric, 10; medical, four; gynaecological, one; orthopaedic, two) and 25 were cared for in the continuing care unit which serves a hospice function. Fourteen patients died in general practitioner beds.

There was a wide variation in the time spent in the hospital by those who died there; a small number were in hospital for months, 36 (49%) were in for less than 10 days and five were in for a few hours only. Reasons for the admission as given by a hospital doctor or as repeated in the notes are shown in Table 1. The mean distance of the district general hospital from the homes of those dying in any of the hospitals was 6.9 miles but for those dying at home the mean was 10.3 miles. Four patients died alone. Generally a nurse was present and in 19 cases out of 41 (46%) the chief lay carer was present (the nurses interviewed were not able to answer this question for the remainder of the patients).

It was not possible to study the small number of terminally ill patients from West Cumbria who died outside the area. Most died in hospitals in Carlisle and Newcastle.

Table 1. Reason(s) for admission for 55 patients dying in hospital as reported by a hospital doctor or as recorded in the notes.

	Number (%) of patients ^a
<i>Social</i>	
Lay carer unable to continue to give care	25 (45)
No lay carer	12 (22)
Other social reason	2 (4)
<i>Medical</i>	
Symptom control	30 (55)
Investigation	13 (24)
Nursing needs	11 (20)
Treatment	7 (13)
Other medical	1 (2)

^aSome patients had more than one reason.

The bulk of the care during the terminal care period took place in the home. Of the patients dying in hospital, 27 were admitted for less than a week (mean 3.8 days); the remaining 47 patients were admitted for a mean duration of 5.0 weeks. Among the patients dying at home, 44 were cared for entirely at home and 39 were admitted during the terminal care period for a mean stay of eight days. Patients dying in hospital following an admission of more than one week formed the hospital-based care group (47 patients); those who were admitted for less than one week together with those who died at home received home-based care (110 patients).

Views of lay carers

In 96% of cases the chief lay carer was a relative, in 82% a woman. There was no significant age difference between the carers' ages in the home death and hospital groups, overall mean 57 years, range 19 to 84 years.

No pressure was put on the lay carers to participate in the study, nor to continue with an interview if they were upset, but the majority were pleased to have the opportunity to discuss their experiences with a sympathetic interviewer. One in 10 of the lay carers described themselves as physically 'exhausted, ill' and a similar number emotionally 'very distressed or depressed, only able to cope with difficulty'. Nearly half of the lay carers (48%) had consulted their general practitioner about their health following the bereavement.

Home deaths. The lay carers' experience of home deaths is based on 53 interviews. In nearly all cases (92%) the carer knew that the patient was dying. The emotional strain was much the commonest difficulty, mentioned by 74% of respondents, while the physical strain presented difficulties for 51%. Problems in relation to the community nurse, unsuitability of the home, finances, and the general practitioner were mentioned by between 7% and 13% of carers. The most worrying aspects of home care for lay carers were medication and their inability to leave the patient unattended (Table 2).

High levels of satisfaction were expressed with the care given by the general practitioners and community nurses, with 92% of both groups rated 'good' or 'excellent'. There were four adverse comments about the primary care teams: a general practitioner was unwilling to attend and unpleasant when he did, another offered little help, there was a 'personality clash' between a community nurse and a carer, and a community nursing team was judged to be disorganized with conflicting advice from different nurses.

Table 2. Worrying aspects of home care for the 53 lay carers interviewed.

	Number (%) of respondents
Anxiety about medication	26 (49)
Inability to leave patient unattended	22 (42)
Not knowing what to expect	18 (34)
Inability to help	15 (28)
Fear of being alone when death took place	11 (21)
Anxiety about what to do when death took place	5 (9)
Anxiety about calling the doctor	3 (6)
Other	5 (9)

Hospital deaths. The lay carers' experience of hospital deaths is based on 41 interviews. A large proportion (41%) said they had not appreciated that the patient was dying. Problems with hospital nurses, transport, lack of support and hospital doctors were experienced by between 7% and 14%.

Again, in general there was a high degree of satisfaction with the care given by the hospital nurses (86% were rated 'good' or 'excellent') and by the hospital doctors (76% were rated 'good' or 'excellent'). A few criticisms were expressed in strong terms. A wife felt that when there was no help for her husband from surgery or radiotherapy '... the doctors finished him off' with regular injections. Another said:

'my husband was treated so badly that I pity anyone having to go through the same ordeal...his diagnosis surely should have been made much sooner and surely his pain, vomiting and sickness should have been better controlled'.

Another said:

'he was very distressed with pain for two days, until they started the syringe pump, why didn't they use it earlier?'

Acute wards were criticized for being busy and noisy.

Views of professional carers

Home care. The general practitioners' view is based on 91 questionnaires completed out of a possible 110 (response rate 83%).

Deputizing services are unknown in this area and virtually all calls, both in normal working hours and out of hours, were made by the patient's general practitioner or colleagues from the same practice.

Twenty general practitioners (22%) felt unable to give the patient the care they wished, in 10 cases owing to problems with the hospital and in six cases owing to difficulty in symptom control. In five cases the consultants were criticized for giving unduly optimistic prognoses, thus making management more difficult. Two regretted syringe drivers were not available for use in the home (these have since been made available).

For 11 of the people receiving care at home, there was little or no community nurse involvement. For the remainder, 68 questionnaires were completed by community nurses, out of a possible 99 (response rate 69%).

Table 3 shows that the largest source of additional support was obtained from Macmillan nurses and the evening nursing service. The nurses felt that practical services and equipment were usually available promptly when required, but in four cases serious delays were experienced.

Three nurses felt unable to give the care they wished because the families were unwilling to accept the nurses' involvement. Two nurses felt their training was inadequate.

Hospital care. For patients receiving care in hospital insufficient questionnaires were completed by junior hospital medical staff for their views to be analysed (response rate 30%).

Table 3. Help received from other sources by 68 patients dying at home as reported by community nurses.

	Number (%) of patients
Macmillan nurse	35 (51)
Evening nursing service	35 (51)
Marie Curie night nurse	14 (21)
None	12 (18)
Special laundry	6 (9)
Social worker	5 (7)
Home help	4 (6)
Health visitor	2 (3)
Meals-on-wheels	1 (1)
Private nurse	0 (0)
Other	0 (0)

However, 100% response was received from the 47 hospital nurses. Many criticisms were voiced by the nurses. A third (34%) felt their nursing training was inadequate for the problems encountered and 30% were unable to give the care they wished, owing to the ward being too short staffed to allow them enough time to attend to the needs of dying patients and their relatives. In three cases doctors were thought to be insufficiently involved, and to be ineffective in controlling pain. On the other hand some nurses were appreciative of the doctors, whom they thought were particularly helpful. Three quotations illustrate the situation in which nurses were placed:

'Sometimes we did not have enough time to spend with X, just to talk or listen to him. He did not have a lot of visitors so a lot of the time he was on his own. I would — we all would — have liked more time to spend and just sit with him.'

'Due to the constant nursing needs of the long stay elderly patients, I was unable to give the dying patient the additional care I would have liked...she needed reassurance every few minutes...I felt this was a call for

help as she would have liked someone with her all the time...a sad and distressing time for all concerned...this case was a frustrating one for me personally as I never seemed to have time enough on our busy ward to give the extra care I would have liked to. Yet the relatives felt we had given a high standard of care and time, above the call of duty.'

'...the doctors seemed reluctant to prescribe larger doses (of diamorphine). I felt helpless and Y always seemed to be in pain. I felt, and so did Y, that dogs don't suffer like this, why should she? This was felt by everyone...she was an extremely brave lady — she could still manage to reassure her family about her dying even though she was scared herself.'

Symptom control

All respondents were asked which symptoms had caused problems (Table 4). The survey did not reveal any differences between the symptoms and the place of care. Predictably, weakness and loss of appetite were frequently present and rarely relieved. The inadequacy of symptom control is also shown in Table 4. 'Partly relieved' and 'unrelieved' symptoms are grouped as 'uncontrolled'.

Discussion

The survey reported here has some weaknesses. The retrospective nature of the study means that observers' recollections may be inaccurate, particularly in the case of the carers, who were interviewed eight weeks after the death and whose responses may have been affected by grief. Consecutive cases were studied to avoid bias in selection, but there is an unavoidable bias in the availability of data. Some of the bereaved carers declined to be interviewed, so that the data is biased towards those who were most satisfied. Professional carers tend to underestimate their patients' symptoms and to overestimate the success of their treatment. Thus the patient's experience is likely to be worse than that assessed by the doctor and the nurse.

Table 4. Percentage of patients with clinical problems and with the symptoms not controlled, as reported by lay carers, doctors and nurses.

Problem	Patients' problems as reported by:					
	Lay carer (n = 93)		Doctor (n = 102)		Nurse (n = 119)	
	% with problem	% uncontrolled	% with problem	% uncontrolled	% with problem	% uncontrolled
Loss of appetite	75	74	58	56	73	68
Weakness	71	69	72	70	82	77
Pain	69	31	65	22	57	15
Nausea and vomiting	40	32	44	25	45	34
Constipation	34	26	34	17	37	18
Breathing difficulty	34	30	25	21	36	34
Confusion	32	30	18	17	26	24
Cough	29	27	22	14	25	22
Sleeplessness	25	23	16	11	18	14
Urinary incontinence	24	19	20	10	30	20
Swallowing difficulty	22	20	22	18	18	16
Depression	22	19	24	19	16	16
Anxiety	20	19	23	20	33	29
Abdominal swelling	16	16	9	8	19	18
Faecal incontinence	10	9	9	6	9	8
Diarrhoea	6	4	6	4	8	5
Itch	5	3	3	2	3	2
Odour	5	4	4	4	8	6
Stoma problems	3	3	2	2	4	3
Other	20	19	18	18	8	6

n = total number of patients for whom report obtained.

Another factor to be considered is that the study was conducted in the summer when the total number of deaths is fewer than in the winter months, and there are relatively fewer deaths of patients over 75 years than in winter.⁸ One would therefore expect a greater number of deaths in hospital in the winter months than in this sample, giving a slightly smaller proportion of home deaths for 12 months than that obtained for April to September. Despite these reservations, the data obtained can be compared with that in other studies.

Surveys in urban areas of deaths from malignant disease show much lower proportions of deaths occurring at home than were found in this study; for example 36% in a London study,⁴ 30% in Edinburgh,² 41% in Sheffield,⁶ between 24% and 35% in eight areas in Trent and Yorkshire.⁹ In West Cumbria 53% of deaths from malignant disease occurred in the home, a figure considerably higher than recorded elsewhere. A number of factors may be responsible.

The availability of a lay person who is willing and able to undertake the work of caring is fundamental to the provision of home care. A strong pattern of marital stability was seen in this group; and in country districts patients often have relatives living nearby and better support from neighbours. In addition, primary care teams in rural areas may have a greater tendency to deal with serious illness in the home than do primary care teams in the cities. Since there are no deputizing services in rural areas the patient and lay carer are attended by a familiar doctor, if not their own, when emergencies arise. Various nursing services are available in addition to community nursing, such as an evening nursing scheme, and Marie Curie nurses when individual nursing is needed. Two Macmillan nurses were available, covering two thirds of the district. In four towns, general practitioner beds were available.

Despite the higher than average proportion of deaths at home in this survey, it is clear that many admissions for terminal care could have been avoided. Half the patients dying in hospital were in for less than 10 days (mean five days); home care could have continued in most of these cases if advice had been provided to the general practitioner on symptom control and if there had been more home nursing and support for the lay carer.

The emphasis placed here on home care in terminal illness is not intended to detract from the important role of the hospital. Even when there is known to be an advanced malignancy, the dangers of assuming the illness is terminal must be remembered.^{10,11} It is important to obtain as precise a clinical diagnosis as possible to be able to give effective palliative treatment, although sometimes the condition of the patient may preclude investigations.¹¹ Admission may be required for diagnostic purposes, for symptom control, for respite care or for continuing care (in particular when there is no carer). There are clear advantages in providing all such services in a specialized unit, with appropriate staffing levels, facilities and expertise, rather than in an acute ward. When care is shared, good communications are essential.

The emotional strain of caring was mentioned by three quarters of lay carers, and this is reflected by the high level of support and counselling needed. There was a marked difference in the lay carers' knowledge of the fatal nature of the patients' illness between the patients who died in hospital (59% known to be dying) and those who died at home (92% known to be dying). The nature of the worries of the lay carers may not always be appreciated by professionals and some are avoidable. In relation to home care, inability to leave the patient unattended was mentioned frequently, but it was disturbing to find half of the lay carers had anxieties about medication. The importance of clear explanations of the purpose of different drugs and unambiguous written directions, using a simple drug sheet, is apparent.

Although lay carers tended to be lavish in their praise for the professional care provided, the proportion of cases where symptoms were inadequately controlled was disappointing. In the case of pain control, depending on the observer, between 15% and

31% of the patients were thought to have uncontrolled pain, yet hospice teams have achieved levels of 8%⁴ and less than 3%.¹² The figures for other uncontrolled symptoms reveal even more striking evidence of avoidable suffering both in hospital and in the home. While good symptom control is the prerequisite of good terminal care, it is not the end of the doctor's responsibility. The aim is to make the last weeks or days not only as comfortable as possible, but also complete and meaningful for both patient and lay carer. The quality of life becomes more important than duration.

There have been dramatic improvements in standards of palliative medicine following developments in hospices over the last 20 years, but inpatient hospices deal with less than 4% of the dying.¹³ The challenge is to apply the lessons learnt there to the generality of home and hospital care of the dying. This cannot be done without more nurses than are normally available in either setting, and without specialized training and support for the nurses. Experience elsewhere has shown the value of an advisory palliative care team, working both in hospital and the home, extending the scope of the Macmillan nursing service and helping to improve levels of symptom control, standards and expectations.^{9,12,13} Advantage should be taken of increased public awareness about such care and use made of voluntary help in day care units, transport and the support of carers. In the case of West Cumbria as many as 70–80% of deaths resulting from incurable malignancy could be in the patient's own home; and irrespective of the place of care, the patient could receive the quality of care associated with hospices.

Postscript

As this survey finished, a local charity, West Cumbria Hospice at Home, made available a new home nursing service for the terminally ill, supplementing existing nursing services. In its first two years of operation it enabled 106 dying patients, most of whom would otherwise have been admitted to hospital, to remain in their homes to the end of their lives.

References

1. Reilly PM, Patten MP. Terminal care in the home. *J R Coll Gen Pract* 1981; **31**: 531-537.
2. Doyle D. Domiciliary terminal care: demands on statutory services. *J R Coll Gen Pract* 1982; **32**: 285-291.
3. Parkes CM. Home or hospital? Terminal care as seen by surviving spouses. *J R Coll Gen Pract* 1978; **28**: 19-30.
4. Parkes CM. 'Hospice' versus 'hospital' care: re-evaluation after 10 years as seen by surviving spouses. *Postgrad Med J* 1984; **50**: 120-124.
5. Ward AWM. Terminal care in malignant disease. *Soc Sci Med* 1972; **8**: 413-420.
6. Ward AWM. Impact of a special unit for terminal care. *Soc Sci Med* 1976; **10**: 373-376.
7. Wilkes E. Dying now. *Lancet* 1984; **1**: 950-952.
8. Cartwright A, Hockey L, Anderson JL. Life before death. London: Routledge and Kegan Paul, 1973: 234.
9. Ward AWM. Home care services — an alternative to hospices? *Community Med* 1987; **9**: 47-54.
10. Rees WD, Dover SB, Low-Bear TS. Patients with terminal cancer who have neither terminal illness nor cancer. *Br Med J* 1987; **295**: 318-319.
11. Saunders C. *The management of terminal malignant disease*. London: Edward Arnold, 1984: 34-35.
12. Doyle D. Domiciliary terminal care. *Practitioner* 1980; **224**: 575-582.
13. Fry J. Deaths and dying. *Update* 1983; **27**: 1706-1707.

Acknowledgements

The research was funded by the Scientific Foundation Board of the Royal College of General Practitioners. An initial study was aided by a grant from the Claire Ward Fund of the British Medical Association. Thanks are due to those who cooperated so helpfully with the questionnaires, both medical and nursing colleagues, and especially the bereaved. The questionnaire can be obtained from the author.

Address for correspondence

Dr E B Herd, South Street Surgery, Cockermouth, Cumbria CA13 9QP.