Death in practice

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SUMMARY. For a nationwide study of terminal care, Gallup Polls took a sample of 950 general practitioners. Fourteen questionnaires could not be delivered; 376 doctors (40 per cent of the register) returned forms; 313 doctors (33.4 per cent) provided information on 301 home deaths and 292 hospital deaths and responded also to statements about care of the dying.

The patients who died at home were well supported by the general practitioner and the family and neighbourhood network. Control of pain was perceived to be better at home. Patients dying at home were more likely to be aware of their impending death. General practitioners usually discussed the imminence of death with relatives, but few relatives and patients raised the question of terminating life. All the available major services were under-used. There was support for more hospices and for more spending on social services. Postgraduate medical education on care of the dying was considered to be inadequate.

Introduction

THE care of the dying is important for general practitioners since 30 per cent of deaths in the United Kingdom occur at home,[1] and even those people who die in hospital have been at home during most of their terminal illness. In terminal cancer the time spent at home is three-and-a-half times that spent in hospital although 60 per cent of these deaths are in hospital.[2] As the number of deaths in hospital increase, Doyle[3] considers that the general practitioner is losing experience and expertise in terminal care.

Studies of death at home have concentrated on localized populations: Sheffield,[4] Glasgow,[5,6] south London,[2] Edinburgh,[3] and Belfast.[7] This study was nationwide.

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Table 1. Sex, age and cause of death of the last patients to die in national sample.

	Percentage of deaths	
	Home ($n=301$)	Hospital ($n=292$)
Sex		
Male	53	53
Female	47	47
Age range (years)		
1-9	1	1
10-29	1	2
30-39	0	1
40-49	5	4
50-59	13	12
60-64	9	7
65-69	13	14
70-74	15	16
75-79	11	13
80-84	17	19
85+	12	9
Not stated	2	2
Cause of death		
Neoplasm	49	33
Circulatory	37	46
Respiratory	13	18
Digestive	0	2
Accident	0	2
Other	12	12

*Answers total more than 100 per cent where more than one cause of death was given.

Aims

The aims of the study were to assess general practitioners':

1. perceived problems with the last patient who died at home;
2. perceived problems with the last patient who died in hospital;
3. attitudes and ethical views on the care of the dying.

Method

A fully structured, part pre-coded questionnaire was sent by Gallup Polls Ltd in summer 1980 to 950 general practitioners selected randomly from lists stratified to represent the correct proportion of each region. The results appeared in computerized, tabular form, thus protecting confidentiality. Information was sought on the last home death, the last hospital death and on 10 attitudinal statements.

Table 2. Responding general practitioners' perception of the awareness of outlook by patients and relatives.

	Home deaths ($n=301$)			Hospital deaths ($n=292$)		
	Yes (%)	No (%)	Don't know (%)	Yes (%)	No (%)	Don't know (%)
Was the patient aware that he/she was dying?	48	50	3	30	66	4
Did the patient raise the subject of dying?	20	79	1	17	81	1
Did you raise with the patient the imminence of death?	13	86	1	8	90	2
Did you discuss with the relatives or friends that the patient was dying?	79	20	1	65	34	2
Did the relatives or friends discuss the termination of the patient's life?	15	84	1	8	92	1
Did the patient ask you to end his/her life?	3	94	3	2	94	4

Table 3. Responding general practitioners' perception of the severity of symptoms before and after treatment.

	Home deaths ($n=301$)			Hospital deaths ($n=292$)		
	Percentage of patients with symptom	Average rating of severity before treatment (1 = least; 5 = most)	Average rating of severity after treatment (1 = least; 5 = most)	Percentage of patients with symptom	Average rating of severity before treatment (1 = least; 5 = most)	Average rating of severity after treatment (1 = least; 5 = most)
Pain	50	3.17	1.61	41	3.29	2.07
Breathlessness	47	3.04	2.16	47	3.45	2.75
Sleeplessness	40	2.70	1.84	32	2.84	2.10
Incontinence	23	2.67	1.96	15	2.49	2.23
Vomiting	22	2.40	1.53	19	2.63	1.84

Results

Nine hundred and fifty questionnaires were mailed, 14 were returned undelivered giving a live register of 936: 376 (40 per cent) general practitioners responded, 63 refusing to take part; 313 (33.4 per cent) completed the form, giving information on 301 home deaths and 292 hospital deaths. Seventeen per cent of respondents were in single-handed practices, 78 per cent in partnership: 16 per cent worked in health centres.

Home deaths

Information was obtained on 301 home deaths; 160 males, 141 females. In 9 per cent of cases hospital admission had been sought and not obtained. The ages at death and diagnoses are listed in Table 1.

In 8 per cent of cases the deceased had lived alone, in 36 per cent with a spouse only, in 28 per cent with the spouse plus others and in 25 per cent with others. In 5 per cent of cases the accommodation was reported as not very suitable.

The frequency of home visits in the terminal stages was daily in 33 per cent of cases, every two or three days in 34 per cent, every four to seven days in 14 per cent and at greater time intervals in 15 per cent.

The respondents considered that in nearly half the cases the patients were aware that they were dying. The imminence of death was usually discussed with relatives, but few relatives and less than 10 patients raised the question of terminating life (Table 2).

Symptoms before and after palliative treatment are shown in Table 3. No mental or emotional problems were recorded in 59 per cent of the deaths (Table 4). The duration of the terminal illness ranged from less than one week to more than five weeks (Table 5). The use of community services is shown in Table 6. In 35 per cent of cases the family cared for the patient on their own, in 58 per cent of cases they required help and in 7 per cent of cases this point was not answered.

Hospital deaths

Information was obtained on 292 deaths in hospital; 155 males, 137 females. The age and diagnoses are reported in Table 1.

In 30 per cent of cases the patients were aware that they were dying. The imminence of death was less often discussed with the relatives or friends, and the question of terminating life was raised by 8 per cent of the relatives and friends and only 2 per cent of the patients (Table 2).

Presence of pain and other symptoms before and after treatment are graded in Table 3.

Mental and emotional problems were considered to be present in over half the cases (Table 4). The presence of symptoms influenced the doctor in calling for admis-

sion in 43 per cent of cases. The duration of the terminal phase is recorded in Table 5.

Attitudinal statements

The responses to the 10 attitudinal statements are shown in Table 7.

Discussion

The purpose of the survey was to gain an impression of general practitioners' problems with the management of their last patient who died at home and their last patient who died in hospital. The disappointing response rate could represent apathy, hostility (several felt angry enough to write) or penury (three wrote requesting a fee). The response rate could perhaps have been increased with a more direct approach, but because of the ethical nature of some of the questions, a direct mailing by Gallup Polls was considered to be preferable. The low response rate masks regional differences.

The majority of deaths were in elderly people. More deaths at home were associated with neoplasms, and relatively more in hospital with circulatory or respiratory disorders. Patients dying at home were more likely to be aware of their impending demise and to have raised the question of the imminence of death with their general practitioner. Place of death made no difference with regard to the subject being raised by the patient. In a survey of 279 patients dying from cancer the doctor thought 46 per cent were aware of the prognosis compared with 54 per cent in the opinion of relatives and carers.[8] However, doctors had discussed the probable outcome with only 13 per cent. Cartwright and colleagues[9] reported that both hospital doctors and general practitioners preferred to tell the relatives rather than the patient. Reilly and Patten[7] showed that 80 per cent of the carers knew that the patient was dying, but this knowledge was not usually shared with the patient; only 18 per cent spoke openly of death. The tendency to tell relatives but not patients must cause strain.

Impending death was more likely to be discussed with the relatives at home, and the question of terminating life was raised by nearly twice as many of the relatives at home than in hospital. The smaller percentage of hospital patients requesting termination of life may reflect the fact that discussion was not held.

The place of death made little difference to the mental or emotional symptoms. In a retrospective study only severe psychological stress will be recorded; as with pain, doctors and relatives differ considerably in their assessment of stress.[7] There was little difference in other symptoms in the two groups.

Pain was a problem. Contrary to the finding of Parkes,[2] control of pain was perceived to be better at

Table 4. Responding general practitioners' perception of the mental or emotional problems of dying patients.

Mental or emotional problems	Percentage of deaths	
	Home ($n=301$)	Hospital ($n=292$)
No, none	*59*	*55*
Yes		
Confusion	*18*	*14*
Fear/anxiety	*15*	*17*
Depression/elation	*12*	*18*
Delirium	*4*	*1*
Paranoid reaction	*1*	*0*
Other	*4*	*4*
Not answered	*1*	*3*

Table 5. Responding general practitioners' perception of the duration of the terminal phase.

Duration of terminal phase (weeks)	Percentage of deaths	
	Home ($n=301$)	Hospital ($n=292$)
1 or less	*17*	*33*
2–4	*35*	*32*
5–9	*15*	*13*
10–14	*8*	*11*
15–19	*1*	*3*
20–24	*5*	*2*
25–29	*2*	*1*
30+	*3*	*2*
Don't know/no answer	*14*	*5*

Table 6. Availability, use of and opinion of facilities and services for dying patients.

	Available to patients (%)	Used (%)	Adequate (%)
District nurse	80	56	55
Night nursing service	42	11	10
Home help	55	8	6
Meals on wheels	51	2	1
Incontinent laundry service	24	4	4
Voluntary workers	21	2	2
Social workers	43	4	3
Others	16	11	10
None/not answered	15	39	40

home. Management of pain was usually reported to be successful, but the treatment of breathlessness, sleeplessness, vomiting and incontinence was less successful.

Twenty-seven patients died at home even though their general practitioner would have preferred them in hospital. The present tendency to decrease the number of hospital beds and reduce inpatient stay means that more dying patients will have to be managed at home. Difficulty in gaining admission may have influenced the support for more hospices and for money being spent on the social services rather than on hospital beds. Martin and Ishino,[10] reporting on the night nursing service in the London borough of Newham, found that the cost of home care—using domiciliary day and night nursing services and other social services, such as meals

Table 7. Responding general practitioners' agreement or disagreement with 10 attitudinal statements, graded on a sliding scale of 5 to 0.

	Percentage of response ($n=301$)					
	Strongly agree (5)	Slightly agree (4)	Neither agree nor disagree (3)	Slightly disagree (2)	Strongly disagree (1)	Not answered (0)
The provision of more hospices is essential to improve the quality of care of the dying	34	17	30	11	6	3
If death is inevitable, doctors should be given the legal right to end life	8	4	13	14	60	1
It is the decision that death is the outcome that is difficult, not the management of the dying when the decision has been made	18	14	23	19	18	7
The control of pain in dying patients is usually not a problem	20	38	19	16	4	2
Doctors fear their own death and therefore cannot counsel the dying	2	7	12	21	55	3
Postgraduate medical education in the care of the dying is inadequate	32	25	26	10	5	2
If money is to be spent anywhere on the care of the dying, it should be spent on the social services instead of providing hospital beds	20	24	24	15	15	2
Exceptional means should not be used to prolong life if death is inevitable	80	11	4	3	2	1
A change in the law to permit euthanasia would not be beneficial for patients who are dying	47	12	15	13	12	1
Given our present circumstances a law to permit euthanasia will be passed before the end of the decade	6	10	17	23	43	1

on wheels and home helps as required—was only about one third of that of a bed in a geriatric ward, or a quarter of the cost of an acute hospital bed. Services at home will have to be expanded: 40 per cent of the deaths at home were of patients aged 75 years and over; people in this age group will increase in number and will be more likely to live alone.

Eighty-four per cent of home deaths occurred in the patient's own home. All the available major services were under-used. The laundry burden arising from incontinence was apparently borne by the informal caring network, for about a quarter of the patients dying at home were incontinent. There were regional differences in the availability of the incontinent laundry service, but numbers were too small for comment in detail. Availability may have been under-reported: Cartwright and colleagues[9] found that doctors were less likely than district nurses to know whether the service was available.

Since the majority disagreed that 'doctors feared their own death and therefore cannot counsel the dying', it is perhaps fear of the patient's reaction that influences the decision not to discuss the subject of death.

Where death was seen to be inevitable, there was considerable agreement with the statement that exceptional means should not be used to prolong life but little agreement that doctors should be given the legal right to end life. The double negative in the question 'a change in the law to permit euthanasia would not be beneficial to dying patients' may have influenced the results: there was a trend among the younger doctors to disagree, but whether this is consequent upon knowledge acquired with age or a changing ethical education with regard to abortion will be apparent only with time.

The general practitioners considered that postgraduate medical education on care of the dying was inadequate. The control of pain in dying patients was not usually considered to be a problem, which implies that education is now needed about management of the person and their social network.

Conclusions

Patients who die at home or in hospital usually have a short terminal phase and those who die at home are well supported by the general practitioner and the family and neighbourhood network. In a minority of cases, hospital admission was requested and denied. Control of symptoms was usually not a problem, but communication with the patient was. The tendency to reduce the number of hospital beds, and length of stay, implies that more dying patients will be managed at home. General practitioners consider that assistance will come from the development of hospices, increased home care services and postgraduate education. They do not believe that legislation to allow the termination of patients' lives would be beneficial.

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Risk of myocardial infarction

To evaluate whether the nicotine and carbon monoxide content of cigarette smoke is related to the risk of nonfatal first myocardial infarction in young men, 502 cases were compared with 835 hospital controls, all between the ages of 30 and 54 years. As expected, the estimated risk of myocardial infarction increased with the number of cigarettes smoked; overall, the relative-risk estimate for current smokers was 2.8 (95 per cent confidence interval, 2.0 to 4.0). The risk did not appear to vary according to the amount of nicotine or carbon monoxide in the cigarette, and the mean amounts of both substances per cigarette were similar for the cases and controls. The results suggest that men who smoke the newer cigarettes with reduced amounts of nicotine and carbon monoxide do not have a lower risk of myocardial infarction than those who smoke cigarettes containing larger amounts of these substances.

Source: Kaufman, D. W., Helmrich, S. P., Rosenberg, L. *et al.* (1983). Nicotine and carbon monoxide content of cigarette smoke and the risk of myocardial infarction in young men. *New England Journal of Medicine,* **308,** 409-413.