Care of the dying in one practice

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SUMMARY. Deaths in a two-doctor semirural dispensing practice with 3,800 patients were studied for 12 months. In this time there were 31 deaths, six of which were sudden and unexpected. Eleven patients died in hospital while undergoing investigation or initial treatment. Only 14 patients required terminal care, three of whom received this entirely in hospital. Six patients died at home and five others were transferred to hospital in the later stages. Consideration is given to the work involved with care of the dying, and also to the services available for patients who die at home. A charitable home nursing service was set up as a result of this study and this is described.

Introduction

THERE have been several excellent studies on terminal care in the community.[1-5] Most authors agree that an ideal system would involve a well-integrated hospital and community service. The community service needs to provide support for both patients and those who care for them. Patients have different needs and resources. By assessing their own care of the dying, individual practitioners may improve the service they offer.

This paper reports an investigation into the terminal care of patients in a semirural practice, with 3,800 patients and two doctors, over a period of 12 months. The study was intended to show:

1. how many patients died in the practice in a year, and how many of these patients required terminal care;
2. how much work was involved with care of the dying in the practice;
3. what help was available for those patients who chose to die at home;
4. whether the community services available to dying patients and their carers could be improved.

Method

The medical records of patients concerned were used to collect and store data. The Family Practitioner Committee (FPC) kindly agreed to let the author retain these notes for the duration of the study.

Deaths were classified in three categories: sudden deaths; deaths in hospital while undergoing initial investigation or treatment; and deaths following terminal care. The age at death, the cause of death and the place where death occurred were noted. The number of home visits made by the partners was counted, the medical problems were listed, and reasons for transfer to hospital were given if this occurred.

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Results

Thirty-one patients died in the practice over the year. Twelve patients (39 per cent) died at home, and the remainder died in hospital. The deaths were classified as described (Table 1).

Sudden deaths

These deaths usually necessitated an urgent visit to attempt resuscitation or confirm death. Bereavement counselling was often required in addition, as the relatives had no warning of impending death. The causes of death are shown in Table 2.

Deaths of patients in hospital for diagnosis or treatment

Many patients require hospital assessment or treatment because of the nature or severity of their illness and may die while receiving it. The causes of death of such patients in this study are shown in Table 3.

Table 1. Number of deaths over one year.

Sudden deaths	6
Deaths in hospital	11
Deaths following terminal care	14
Domiciliary terminal care (6)	
Hospital terminal care (3)	
Shared terminal care (5)	
Total	31

Table 2. Details of sudden deaths.

Sex	Age (years)	Place	Diagnosis
M	55	Home	Myocardial infarction
M	60	Home	Stroke
M	73	Home	Fatal burns
F	77	Home	Heart failure
M	82	Home	Myocardial infarction
M	84	Home	Myocardial infarction

Deaths following terminal care

Three patients who received all their terminal care in hospital were long-term geriatric inpatients (Table 4). Five patients spent much of their last illness at home but were admitted before death (Table 5). The reasons for admission varied. Three patients had close relatives available, but they were not prepared to help in home care, even though two of these patients openly asked to die at home. None of these relatives appeared to have guilt or bereavement problems after death. One patient with a long-standing multi-infarct dementia had to be admitted because of exhausted carers and he subsequently died of a stroke in hospital. Despite the impossibility of home care, his relatives had many feelings of guilt. One patient was well cared for by his sister-in-law but was admitted in terminal coma at her request because she 'did not want a death in the house.' All of these patients were readily admitted to hospital after telephone contact with the consultant concerned and none of the relatives made complaints about the care received in hospital.

Table 3. Details of deaths in hospital during investigation or treatment.

Sex	Age (years)	Diagnosis
M	4 days	Birth asphyxia. Second twin
M	60	Hepatic failure. Alcoholic cirrhosis
M	67	Cerebrovascular accident
M	67	Renal failure. Lymphoma
M	67	Fat embolism. Fractured femur
M	70	Cerebrovascular accident
F	71	Bronchopneumonia. Diabetes mellitus
F	71	Post-vulvectomy pulmonary embolus. Carcinoma of vulva
M	77	Pre-renal renal failure. Dehydration from endogenous depression
M	88	Bronchopneumonia. Chronic bronchitis
F	89	Intestinal obstruction. Carcinoma of rectum

Table 4. Details of hospital terminal care.

Sex	Age (years)	Cause of death	Long-term problem
M	68	Stroke	Peripheral vascular disease. Diabetes. Heavy nursing requirements
M	79	Bronchopneumonia	Respiratory cripple. Cor pulmonale. Chronic bronchitis. No living relatives
F	87	Stroke	Cerebrovascular disease. Poor recovery from previous stroke

Discussion

Using the place of death as the only measure of terminal care may give an erroneous view of the situation. Terminal care may be given in hospital, in the patient's home or shared between the two places. In the year of the study only three patients had terminal care entirely in hospital, the other 11 patients received most or all of their care at home (Tables 5 and 6). Even so, hospital admission should not be seen by the doctor or relatives as a failure of domiciliary care, as the patient or relatives may prefer hospital and admission may be the only solution when nursing requirements are heavy or carers unavailable. In one case when the patient chose to die at home, the general practitioners put pressure on friends and relatives by asking them to help, but this intervention was obviously resented. The relatives phoned a consultant to arrange admission without informing the doctor, and this reflected a breakdown of trust.

It has been said that attitudes towards death correspond to our attitudes towards life.[6] The depth of love that relatives and friends feel for a dying person may be reflected in the care they provide. In some of our cases where love appeared deepest, the relative felt their efforts had been insufficient even when this was clearly not so. One old lady, for example, could not forgive herself for being in the kitchen making tea when her husband finally died after months of devoted care at home.

Five of the six patients who died at home had discussed approaching death with their carers and doctor. One of these patients had been informed that he

Table 5. Details of shared terminal care.

Sex	Age (years)	Carers	Diagnosis	Number of visits from doctor	Illness at home (weeks)	Illness in hospital (weeks)
F	64	Sister plus friends	Carcinomatosis	5	8	1
M	64	Sister-in-law	Ca pancreas	5	7	48 hours
F	75	Husband	Ca oesphagus	6	9	2
M	83	Wife plus son	Dementia. Stroke	10	30	6
F	86	Private nurse plus daughter	Myocardial infarction	8	6	1

Ca = carcinoma.

Table 6. Details of home terminal care.

Sex	Age (years)	Carers	Diagnosis	Number of visits by doctor	Illness (weeks)
M	58	Wife	Ca bronchus	15	16
F	63	Husband	Ca rectum	50+	48
M	76	Wife	Ca bronchus	12	12
F	81	Daughter	Myocardial infarction	5	1
M	82	Wife	Cor pulmonale Chronic bronchitis	50+	52
F	87	Daughter	Stroke	3	1

Ca = carcinoma.

Table 7. Help available.

Relatives and friends	
Primary health care team	Community nurse
	Doctor
	Health visitor
	Physiotherapist
Home nurse	Private
	Marie-Curie
	Macmillan
	Nightingale Nursing Fund
Hospital	Domiciliary visits
	Short admissions
Social services	Attendance allowance
	Supplementary benefit
	Non-contributory pension
	Home help
	Meals-on-wheels
	Home help night sitters
Equipment (various sources)	Sheepskins, oxygen, hoists, ripple bed, etc.
Church and mutual support groups (for example, Multiple Sclerosis Society, Muscular Dystrophy Society)	
Bereavement groups (for example, Society of Compassionate Friends, Cruse).	

had terminal cancer by a junior hospital doctor without prior consultation with his wife. This information was taken calmly by the patient and he discussed it freely on several occasions before he died peacefully at home. His wife, however, was deeply upset that he had been told and had a prolonged and stormy bereavement. In four other cases the knowledge of death appeared to facilitate communication between patient, carer and doctor. The sixth patient was unable to speak following a stroke.

Carers with heavy nursing duties over a long period of time frequently become physically and mentally exhausted. In one case this led to the patient's admission and subsequent death in hospital, and both wife and son felt they had let their loved-one down. In response to this problem a nursing charity has been set up to serve our practice area. The Nightingale Nursing Fund was formed with a committee of three district nurses in our area and four other invited members to act as chairman, secretary, treasurer and fund-raiser. A constitution was drafted, a geographical area delineated, and funds raised to employ private nurses at commercial rates to look after patients in their homes. Anyone living in the area covered by the charity may receive this service, whether they are patients of this or another practice. Any severe illness is included in the scheme whether terminal or not, the eligibility being determined by the district nurses or by the committee if there are problems. In the first instance relatives are offered forty hours of free home nursing to use either during the day or at night. The scheme is proving very useful and will be described more fully after the first year of operation.

Recent developments in terminal care include the spread of hospices and the setting up of home care services associated with them.[7] The hospice movement in our area has yet to commence services although we now have the help of Macmillan Nurses, funded initially by the National Society for Cancer Relief. The extent of the help available to patients in our practice choosing to die at home is summarized in Table 7. The Nightingale Nursing Fund is particularly useful because it is immediately available in times of crisis and because it is not limited to dealing with one particular disease, such as cancer.

This study has demonstrated the relatively small part that terminal care plays in terms of workload for the general practitioner, but its importance in terms of care, support and use of facilities. With the resources that are or can be made available the general practitioner faces an important challenge to provide and organize care of the highest quality for those who choose to die at home. We must meet this challenge.

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