

Terminal care in the home

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SUMMARY. We report on a 16-week study of the terminal care given to 118 patients who died at home at the end of a chronic illness. We describe the clinical features of the care and how these were managed, we compare the doctors' and relatives' view of the patients' suffering and awareness of death, and we explore the implications of death at home for general practitioner, nursing and other support services and for the relatives who care for the patient.

Introduction

FORWARD planning and allocation of resources for terminal care is a task faced by each NHS district. Predictions can be made about the future age-sex structure of the population, how many patients will die in a year, the pattern of these deaths and the proportion of them that will be preceded by a prolonged illness. What is less clear is what proportion of these deaths could and should be managed by general practitioners and other primary care colleagues, how many patients will require hospital beds and the extent and character of the contribution made by secondary care services (domiciliary, outpatients, brief admissions and so on) to the management of the terminally ill at home. The advent of hospices as part of NHS services and of discussions about their funding has highlighted how little we know about patterns of need.

Ford and Pincherle (1978) have described the present options. Hinton (1979) has compared the care of patients treated adequately in the hospital, as outpatients and in hospices but was unable to demonstrate major differences. However, two previous studies (Levy and Sclare, 1976; Parkes, 1978) have noted some of the problems of home care, including the burden on rela-

tives and the difficulty of relieving chronic pain. Studies of principally clinical interest, such as Twycross (1974), have been complemented by administrative studies (for example, Wilkes *et al.*, 1978) which examine the revenue consequences of community facilities such as the day-hospital for terminal care. Recent editorials (*Lancet*, 1980) have acknowledged the need to plan hospice care carefully and have explored the implications of the hospice for the range of provision.

Aims

Our intention is to describe two linked studies of the management of terminal illness. The first study is reported here and was of deaths (excluding sudden deaths) which took place in the home. It had the following aims:

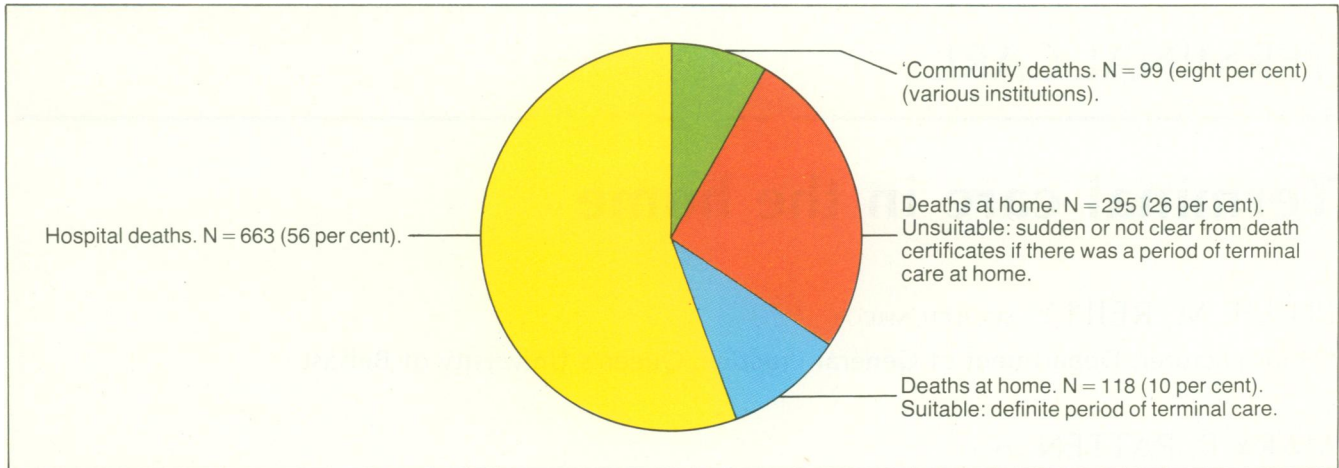
1. To note which patients died at home after a period of terminal care.
2. To describe the care of these patients at home.
3. To describe aspects of doctor-patient communication about the impending death.
4. To describe the experience of the closest carer.

The second study is of patients with similar terminal conditions but who die in hospital and is being carried out now. It will explore the clinical and social factors which are associated with admission and death in hospital rather than in the home.

Method

Between September 1979 and January 1980 we looked at all death certificates from Greater Belfast. Through contact with the general practitioner, great care was taken to identify deaths at home which were preceded by a period of terminal care. We then sent a questionnaire* to the general practitioner which requested demographic details of the patient, clinical and treatment

*Copies of the questionnaire are available from the authors.



Deaths in Belfast, September 1979—January 1980.

features, aspects of nursing and practical care and an assessment of the doctor-patient communication. We also sent a letter to the 'informant', that is the person who registered the death, asking them if we might contact the person who looked after the deceased at home (the closest carer). We then arranged for the carer to be visited by one of six interviewers, each covering a particular area of Belfast. They included district nurses, health visitors and experienced community workers. They met us at regular intervals to discuss the interviews, which were completed by means of questionnaires similar to those sent out to general practitioners. We computed the questionnaires and obtained results by using SPSS (Statistical Packages for the Social Sciences) methods.

Results

During the 16 weeks of the study there were 1,175 deaths in a population of 421,300. The distribution by type and place of death is indicated in the Figure. The 118 deaths which met the criteria of being preceded by a definite period of terminal care formed the study population.

Response rate

Seventy-five questionnaires were returned by 61 general practitioners, a response rate of 63.5 per cent. Seventy-eight questionnaires were returned by the closest caring person, a response rate of 66 per cent. Both questionnaires were completed for 49 patients (41.5 per cent).

Patients and their care (Aims 1 and 2)

The majority were over 80 years of age. In the group of 75 patients for whom general practitioners returned questionnaires, there were 37 males and 38 females. More than half were married and more than a third were widowed. There were patients from every social class and at least one from each postal district of Belfast.

Table 1. Predominant process responsible for terminal episode (general practitioner replies (75)).

	Number of patients
Cardiovascular disease	12 (16%)
Cerebrovascular disease	11 (15%)
Neurological disease	2 (2%)
Respiratory disease	14 (18%)
Neoplastic disease	36 (48%)

Table 2. Length of terminal episode*.

Duration	Number of patients
< 1 week	16 (21%)
1-4 weeks	13 (17%)
1-3 months	17 (23%)
> 3 months	29 (39%)

*The terminal episode begins when, following accurate diagnosis, the advent of death is certain and not too far distant and where treatment has changed from curative to palliative (DHSS, 1980).

In this group of patients the terminal episode (Table 1) was preceded by normal health in 20 per cent, confinement to the house in 60 per cent and "mainly bedfast" in the remaining 20 per cent. One half of the whole group had had an episode of serious illness (stroke, myocardial infarction and so on) in the last decade. The lengths of the terminal episodes are summarized in Table 2. Almost 90 per cent of the group was cared for by the immediate family, usually spouse or child. A minority was looked after by more distant family or neighbours, even though seven patients lived alone. Many relatives were themselves elderly and infirm.

Home care of the patient presented problems for the general practitioner in one third of cases, mainly because management of clinical problems was difficult.

Table 3. Clinical problems.

Problem	Number of instances	
	General practitioner replies (75)	Carer replies (78)
Pain	35	41
Weakness	55	63
Sleeplessness	22	39
Confusion	16	37
Depression	10	28
Anxiety	13	18
Cough	19	34
Breathing difficulty	32	43
Dysphagia	6	17
Dry mouth/thirst	15	41
Loss of appetite	40	58
Nausea	19	27
Constipation	11	38
Diarrhoea	5	16
Incontinence: bladder	15	36
Incontinence: bowel	9	23
Pressure sores	11	35
Local growths	2	4
Incisions: complications	1	7
Itch	1	7

Table 4. Medication problems.

Medication	Cases	Number unsatisfactory
Hypnotics	22	10
Antibiotics	25	12
Laxatives	17	9

(For the range of clinical problems, see Table 3.) There were considerable differences between the general practitioners' and the carers' perceptions of the patients' problems.

Medication

Half of the general practitioners were less than satisfied with the drugs they used. Three main groups of medication (Table 4) contributed to this dissatisfaction because they were ineffective, because of the frequency with which they caused side-effects or both.

Analgesics were prescribed for 55 patients, indicating that pain was not an inevitable feature of terminal care. However, some disappointment was expressed by the general practitioners in 20 per cent of instances where analgesics were prescribed of whatever strength. Tranquillizers were used in 31 patients and diuretics in 25 patients with no dissatisfaction. Over three quarters of the cough suppressants and digoxin prescribed were satisfactory.

Table 5. Home visits by general practitioners.

Frequency	09.00-18.00		Out-of-hours	
	Number of patients	Frequency	Number of patients	Frequency
None	2	None	16	
Once	4	Once	18	
2-10 visits	37	2-5 visits	27	
More than 10	32	More than 5	14	

Nursing and other care

Three quarters of patients received daily nursing. In many cases twice-daily visits were paid and a wide range of services was provided. These included advice on self-care, injections, dressings, enemas, suppositories, skin care and help with turning and supervision of the patients. The number of district nurse visits to this patient group was of the order of 10,000 (an average of 120 visits per patient). A small number of relatives reported difficulties in obtaining sufficient nursing care—particularly at the time they needed it. The general practitioner was not always aware of these problems.

Health visitors were recorded as having helped in the care of only 18 patients. There was direct social work involvement in only two cases but social workers were indirectly involved through the home help services in a further 12 instances. There was very limited use of other services (night-sitters, laundry, financial assistance) and even of practical aids. The interviewers observed that relatives were largely unaware of help other than nursing care.

Visits by general practitioners (Table 5)

Forty-five patients were visited by the same general practitioner throughout the terminal episode. Of the remaining 30 cases, 16 were also visited by partners of the general practitioner concerned and 14 were also visited by general practitioners with whom the original doctor worked in a rota. The number of home visits by general practitioners to this patient group was of the order of 1,000 (an average of 12 home visits per patient).

Other medical care

Nineteen patients were admitted briefly to hospital during their terminal episode; an additional nine patients attended outpatient departments and two patients received domiciliary visits by consultants. Thus 30 patients had some contact with secondary care. The general practitioners reported that communication and other aspects of the care of this group was unsatisfactory in 11 cases.

Table 6. Patients' experience according to replies from general practitioners and carers.

	General practitioner replies (75) (per cent)	Carer replies (78) (per cent)
<i>Physical suffering</i>		
Severe	15	36
Moderate	39	17
Slight	24	17
Not at all	21	21
Not known	1	9
<i>Psychological distress</i>		
Severe	3	17
Moderate	29	13
Slight	29	13
Not at all	35	47
Not known	4	10

Table 7. Aspects of communication with patient.

	General practitioner replies (75) (per cent)	Carer replies (78) (per cent)
<i>Did you speak of dying with the patient:</i>		
Openly?	8	18
Obliquely?	27	13
Not at all?	65	69

Patients' experience (Table 6)

There were substantial differences between the general practitioners and the carers in the perception of intensity of physical suffering and psychological distress.

Communication with the patients (Aim 3)

The general practitioners were aware of the terminal nature of the episode in over 90 per cent of cases. They described their involvement with the patient as close in over one third of cases, yet only eight per cent spoke openly with the patient of their impending death (Table 7). Fewer carers (81 per cent) appreciated that the patient would die; less than one third (31 per cent) spoke with the patient either openly or obliquely. Even in the intimate situation of home care the majority of general practitioners (65 per cent of cases) and relatives (69 per cent of cases) did not broach discussion of the impending death with the patient.

Table 8 indicates that almost half the patients asked either directly or indirectly how their illness might progress and that, where patients had some awareness of the truth (general practitioners' perceptions, 29 per cent; carers' perceptions, 38 per cent), they experienced feelings of general acceptance.

Table 8. Aspects of communication with patient.

	General practitioner replies (75) (per cent)	Carer replies (78) (per cent)
<i>Did patient ask how illness might progress:</i>		
Openly?	16	22
Obliquely?	28	26
Not at all?	56	52
<i>If patient did communicate anything regarding the prognosis, was this with a sense of:</i>		
Awareness of truth?	29	38
Lack of awareness?	15	10
Not applicable	56	52
<i>If there was some degree of awareness of the truth, was the patient's attitude:</i>		
Varying acceptance?	7	9
General acceptance?	20	26
General rejection?	2	3
Not applicable	71	62

The carers' experience (Aim 4)

The carer knew that the deceased was terminally ill in over 80 per cent of cases. Home care was difficult in 40 per cent of cases, chiefly due to physical and mental strain. Carers mentioned much less frequently the unsuitability of the home, financial constraints and lack of support from relatives who had other commitments.

The majority of carers (48) were not worried by having to care for a serious illness. Of the 30 who were, anxiety about medication and about how to help the patient, especially immediately after death, were much more frequently expressed than anxiety about contacting the general practitioner.

When asked how they felt at the time of interview (within three weeks of the death), 20 per cent of the carers said they were physically exhausted and psychologically very distressed. One quarter said that they had gone to see their general practitioner. Nevertheless, the overwhelming impression given to the interviewers was that for the majority of families the experience of caring for a dying relative at home had been profoundly satisfying. Very few other forms of care (hospital, nursing homes) would have been preferred had these been available. Hospice care (defined) plus medical and nursing service from a hospice was acceptable to a minority only. Yet many of the carers felt that they could not have coped if the terminal phase had lasted much longer.

In the case of the general practitioners, hospice care plus a medical and/or nursing advisory service was much more acceptable. If available, half of the general practitioners thought that the best method of administration would be through permanent staff, but over one

third wished to look after their own patients within the hospice. The 61 general practitioners involved in the study identified a total of 131 patients who had died in the preceding year who would have benefited from hospice care.

Discussion

This study of terminal care in an urban population has shown that as few as 10 per cent of patients die in their own homes at the conclusion of what was recognized to be the last illness. Yet relatives described the experience of caring for a dying family member as deeply satisfying. This care was accomplished even in surprisingly poor housing conditions by elderly and frail spouses and was sustained for weeks and even months.

There were very few instances in which at the conclusion of the illness the general practitioner, with hindsight, would have chosen an alternative to home care. There were no complaints by relatives that general practitioners were difficult to contact or did not call sufficiently often, and the profile of visits by general practitioners showed remarkable continuity of care, not just among the practice doctors, but usually by the same doctor. Even greater support seems to have been offered by nursing services in terms of availability, continuity and range of care.

Yet strain was undoubtedly experienced by both professional staff and relatives. The general practitioners reported that in a third of the cases the patient had been difficult to care for at home and that this was because of clinical problems. The therapeutic task was one of considerable complexity because of the range of symptoms suffered by any one patient, with rapid alteration in symptom pattern, and because of the wide variation in signs and symptoms between patients with the same terminal illness. Pain was a clinical problem in approximately half of the patients, but doctors were dissatisfied with analgesics in 20 per cent of the cases in which they were used. The level of dissatisfaction rose to 50 per cent in other categories of medication such as laxatives, hypnotics and antibiotics.

Even where therapeutic problems were considerable, there appeared to have been relatively little consultation with hospital staff. Almost half of the patients had used secondary care in some way—brief admission, out-patient or domiciliary appointments—but in more than a third of these instances the general practitioner complained that communication back to him had been poor.

The relatives were very conscious of physical suffering and psychological distress and their perception of pain was higher than that of professional workers. Irrespective of the length of illness, relatives reported that they could not have nursed the patient if the illness had continued for much longer. Surprisingly, they complained little of the practical difficulties of home care, even though problems of laundry and finance

must have been considerable and there had been little use made of statutory services such as home-help, laundry or meals on wheels. The focus of what had troubled them was psychological—what would happen at the moment of death and how they would cope with this.

If the problems are perceived as psychological, so too are the advantages. Although death was rarely discussed openly between relative and patient or doctor and patient, doctors and relatives reported a sense of being close to the patient.

The issues raised by this paper are those concerned with planning for terminal care. General practitioners need to be better supported in their therapeutic management. Caring relatives need advice about the services available and encouraged to use them. There is a need for counselling skills, so that relatives and possibly patients can be helped to talk about death. However, all these improvements are at present relevant to only 10 per cent of the potential population. The key question is, why is it that so few patients are cared for at home?

References

- Ford, G. R. & Pincherle, G. (1978). Arrangements for terminal care in the NHS (especially those for cancer patients). *Health Trends*, **10**, 73-76.
- Hinton, J. (1979). Comparison of places and policies for terminal care. *Lancet*, **1**, 29-32.
- Lancet* (1980). Changing the face of death. Editorial, **1**, 1340-1341.
- Levy, B. & Sclare, A. B. (1976). Fatal illness in general practice. *Journal of the Royal College of General Practitioners*, **26**, 303-307.
- Parkes, C. M. (1978). Home or hospital? Terminal care as seen by surviving spouses. *Journal of the Royal College of General Practitioners*, **28**, 19-30.
- Twycross, R. G. (1974). Clinical experience with diamorphine in advanced malignant disease. *International Journal of Clinical Pharmacology*, **9**, 184-198.
- Wilkes, E., Crowther, A. G. O. & Greaves, C. W. K. H. (1978). A different kind of day hospital—for patients with preterminal cancer and chronic disease. *British Medical Journal*, **2**, 1053-1056.
- Department of Health and Social Security (1980). *Working Party on Terminal Care*. Report. Chairman: Wilkes, E. London: HMSO.

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