

Domiciliary terminal care: demands on statutory services

DEREK DOYLE, MB, FRCCP

Medical Director, St Columba's Hospice, Edinburgh

SUMMARY. The work of a specialist advisory home care service for the terminally ill during 1980 is reported, with reference to the demands it made on community services. Whilst there was no change in demand for home helps, there was a 44 per cent increase in visiting by community nurses for male patients and a 117 per cent increase for female patients. Commodes, ripple mattresses and backrests were all essential and an increased need of over 100 per cent in each was recorded. Patients were attended on average for three months (men) and six months (women) and 41 per cent were able to remain at home until their death.

Introduction

SEVERAL home care services for the terminally ill now operate in Britain, most of them based on hospice-type units. All are principally concerned with patients in the later stages of cancer. This paper is based on the work of the Macmillan Home Care Service in Edinburgh, operated by St Columba's Hospice since it was set up in December 1977. The service is generously funded by the National Society for Cancer Relief.

The service is staffed by three nursing sisters who are qualified in health visiting, experienced in community nursing and hold the JBCNS Certificate in Terminal Care Nursing. Medical help is provided by the three hospice doctors, two of whom are full-time; the third is a part-time general practitioner. The advice and services of a hospice social work assistant, a physiotherapist and an occupational therapist attached to the hospice are also available. These workers operate only within the city of Edinburgh (population 500,000) and become involved only at the invitation of a patient's general practitioner, who remains in clinical charge at all times.

The aim of the service is to give to the patients, their families and professional attendants specialist, professional advice and support which will improve the quality of life and the care the patients receive. A

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secondary aim is to enable more patients to remain at home longer than might otherwise have been possible, and even die at home if that is their wish.

Practical nursing continues to be provided by local authority community nurses and night sitters funded by the Marie Curie Foundation through the Community Nursing Service; essential nursing aids and equipment are supplied by the authority. This paper looks at the work done by the service in 1980 and reviews its effect on these statutory community services.

Methods

Records were completed by the staff of the Macmillan Home Care Service in respect of all 227 patients referred to it in 1980. A note was kept of the following: details of diagnosis; symptomatology; community nurse attendances at the time the service was called in and at the end of domiciliary care (whether the patient had died at home or been admitted to a hospital/hospice); nursing equipment in use at these two times: commodes, hospital beds, 'ripple' mattresses (or similar types), back rests, oxygen equipment and suction apparatus (no records were kept of bedpans, urinals, sheepskins, liquidizers and feeding cups, many of which we found were purchased for the patients by their families); home help involvement; the provision of meals on wheels; and the services of Marie Curie night sitters. The information was transferred to punch cards for analysis.

Results

Two hundred and twenty-seven patients were referred to the service in 1980 (107 men and 120 women), all with cancer (Figure 1). Their average ages were 64 (men) and 65 (women); the youngest patient was 16 and the oldest was 91. Average time with the service was 97 days (men) and 166 days (women). This was considerably longer than in the two previous years (Figure 2). The men were seen, on average, 33 times, the women 53 times by a sister or doctor from the hospice (not including subsequent bereavement visits). Forty-one per cent of the patients died at home (Figure 3).

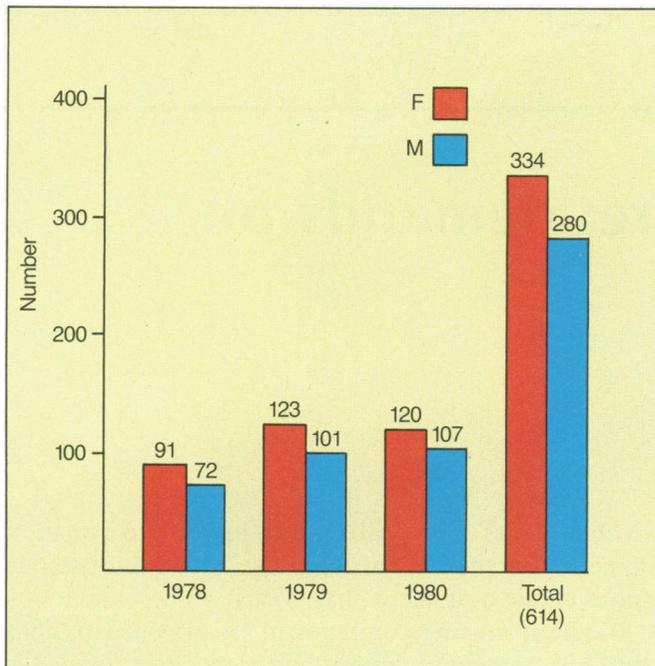


Figure 1. Number of patients.

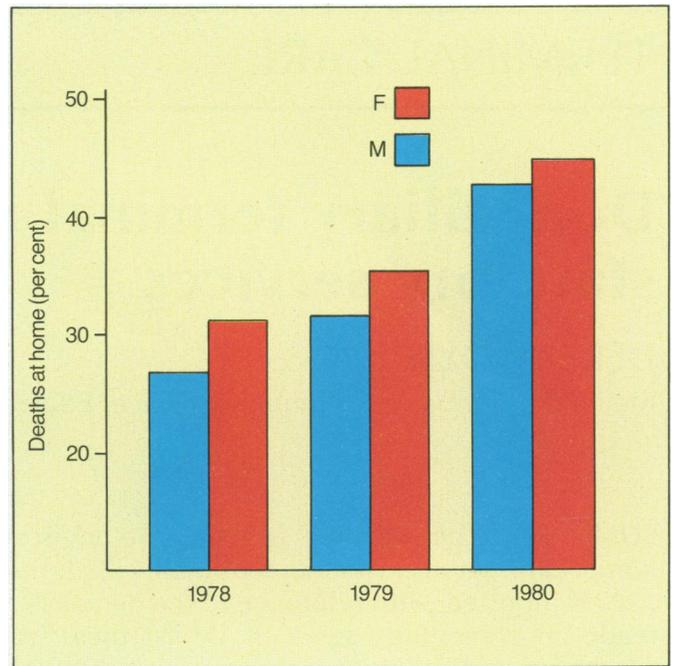


Figure 3. Deaths at home

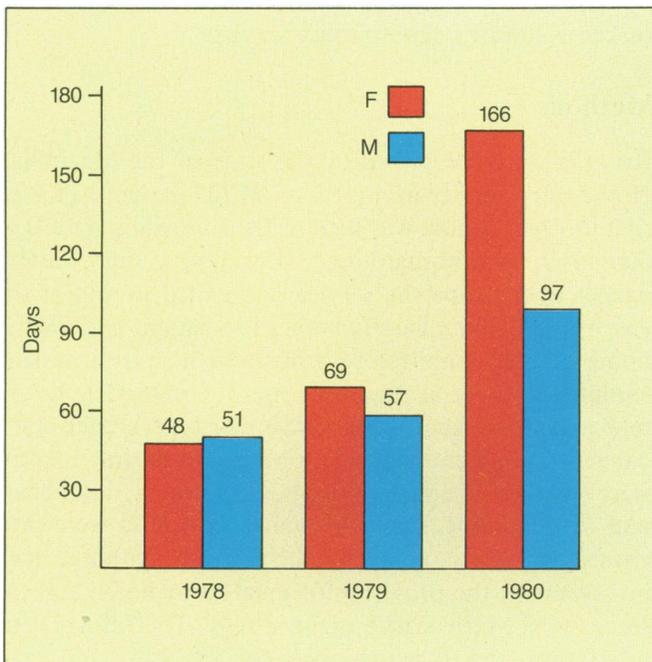


Figure 2. Time with the service.

Community nursing

Figure 4 shows the attendances of community nurses (district nurses), but does not attempt to report details of the nursing care given nor the time spent with the patient at each visit. When the home care service team was first involved, 48 men (45 per cent of the total) and 69 women (58 per cent) were attended by a community nurse, almost equal numbers receiving weekly or daily visits. When terminal care at home was discontinued there was little change in the proportions being visited

(42 per cent of the men and 61 per cent of the women). However, the pattern of visiting had changed considerably. It had increased from a total of 263 to 378 visits a week for men (a 44 per cent increase) and from 313 to 680 visits for women (a 117 per cent increase). The most common pattern remained once daily, but fewer patients now had only weekly or twice-weekly visits.

Other services

The results for night sitters, home helps and nursing equipment are shown in the Table. Use of night sitters increased for both men and women; the demand for home helps remained much the same, but total visits per week dropped from 30 to 25 for men. Only one woman needed a hospital bed on loan; two needed a suction machine. None of the men and only 2 per cent of the women received meals on wheels. None of the patients was using oxygen.

Discussion

The increase in workload and frequency of visiting by district nurses is no surprise. What is surprising is that only 45 per cent of men and 58 per cent of women, (overall average 52 per cent) had the services of a nurse when a specialist advisory service was called in, and that on the completion of domiciliary care still only 52 per cent had a district nurse. In view of the seriousness of the patients' conditions it is equally interesting that so few patients had twice- or thrice-daily visits.

A possible relation between the severity of symptoms and the attendance of community nurses was looked at but no pattern was found. Some patients with pressure sores or fungating cancers were not being visited when

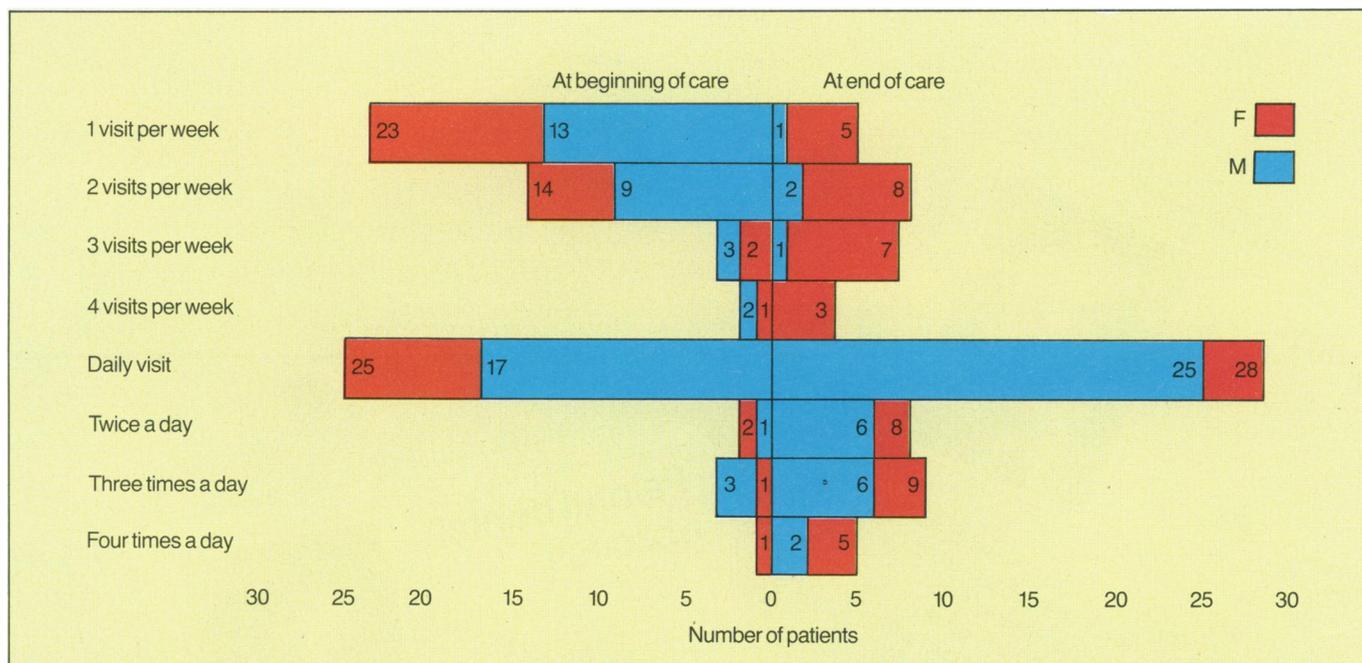


Figure 4. Pattern of community nurse attendances at the beginning and at the end of care.

the home care service was called in, whilst others who needed only a bed-bath and minimal general nursing care were attended thrice daily. As in previous studies at St Columba's Hospice, it was found that 20 per cent of faecally incontinent patients had no nurse.

It might be argued that the identification of these needs and the mobilization of staff and skills to deal with them are themselves reasons for a domiciliary cancer service. These findings might equally be a demonstration of the reluctance of many patients and their families to mention some of their problems to a doctor, to have outsiders in their homes or even to have to admit to needing help. In a city where over 65 per cent of community nurses are attached to general practices, the results also raise the question of whether or not these needs, if they were known to attending doctors, were brought to the notice of nursing colleagues in the primary health care teams. How, it must be asked, are the needs of the terminally ill (or indeed the seriously ill from any cause) assessed, met and monitored? Is it as casual as some of the above figures tend to suggest?

The unchanged demand for home helps at a time of terminal illness is probably predictable. Home helps are indispensable for the domestic needs of a household where a person is dying, but such needs (homecleaning, shopping, preparing meals) change little in comparison with the rapidly altering nursing and medical needs, which are reflected in the figures for nursing and the workload of the domiciliary support service.

The supply of equipment raises important questions. Regrettably, no accurate figures were kept in this study of equipment supplied by the local authority stores and that loaned by the hospice. From the outset it has been a policy of St Columba's Hospice never to attempt to do

Percentage of patients receiving services at the beginning and end of care.

	Beginning of care	End of care
Marie Curie night sitters		
Men	2.0	15.0
Women	0.8	10.0
Home helps		
Men	9.0	8.0
Women	20.0	20.0
Commodes		
Men	9.0	29.0
Women	19.0	46.0
Ripple mattresses		
Men	4.0	10.0
Women	0.0	11.0
Back rests		
Men	5.0	9.0
Women	3.0	11.0

what, by rights, should be done by statutory authorities. The supply of commodes, back rests and so on was such a case, but it soon became clear that some equipment was always in short supply. On many occasions a patient had to be placed on a waiting list, even for a commode, and occasionally the need for it was so urgent that failure to supply it would have meant inadequate care, possible clinical complications, increased family strain and early hospital admission. Therefore a small stock of most items was built up in the hospice for short-term loan to these patients until the local authority could supply them. Undoubtedly some patients would have had to be admitted to hospital or hospice much earlier had such basic items as commodes,

ripple mattresses, Flotron intermittent compression pumps and back rests not been made available by the hospice.

Finally, if we look at night sitters organized by the community nursing service but funded by the Marie-Curie Foundation, it is surprising that only 15 per cent of men and 10 per cent of women had them. The impression of all of us working with the dying at home is that the time of greatest patient fear, apprehension and loneliness is at night. Similarly, it is the weeks of attendance on a loved one at night which so quickly strain a family and lead to hospice admission. When 59 per cent of the study patients eventually had to become inpatients and died within weeks, there can be no doubt of the seriousness of their condition, yet seldom in Edinburgh can a sitter be provided more than thrice weekly for more than a few weeks. Were such sitters unobtainable, not offered, or just not acceptable to families who feared further intrusion of more professional helpers into the privacy of their homes?

Turning to more positive aspects of this study, it is clear that we need not assume that, according to the national pattern, only 30 per cent of patients are able to die at home in our cities and that 70 per cent have to be admitted, bringing an immediate sense of relief to families, but also producing a feeling of guilt that they may have failed in some way. Over 41 per cent of the study patients died at home and the impression is that nearer 50 per cent could do so if more night help was available. The study also demonstrates that good terminal care starts long before death. Figure 2 shows the steadily lengthening time the service is involved with patients. This finding is a tribute to the general practitioners who used the service and recognized the many benefits of calling on it at an early stage, when much can be done through expert pain and symptom relief, through co-operation with nursing colleagues and through skilled support and education of the families.

Two of the skills of good terminal care are intelligent anticipation of problems and well-planned use of the many professional services available in good general practice. These will range from early provision of equipment and discussion with specialist colleagues, (such as home care service teams) to awareness and use of the skills and resources of community nurses. Clearly, domiciliary terminal care will bring extra work to the nurses, but it will also bring extra professional satisfaction. If our dying patients want to be at home, as more than 50 per cent assure us they do, doctors must face the challenge.

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Address for reprints

Dr D. Doyle, St Columba's Hospice, Challenger Lodge, Boswell Road, Edinburgh EH5 3RW.

FOURTH NATIONAL TRAINEE CONFERENCE REPORT, RECOMMENDATIONS AND QUESTIONNAIRE

Occasional Paper 18

How much teaching do vocational trainees really get? What do they think about their trainers and how easily can they talk to them? This *Occasional Paper* reports on the proceedings of the Fourth National Trainee Conference held at Exeter in July 1980 and analyses the results of a questionnaire which was returned by 1,680 trainees throughout the country. This is the most detailed information so far published about the opinions of trainees, and from them a new 'value for money' index has been derived, based on sophisticated statistical analysis, which now makes it possible for the first time to rate a general practitioner trainer.

Fourth National Trainee Conference, Occasional Paper 18, is available now from the Publication Sales Department, Royal College of General Practitioners, 14 Princes Gate, Hyde Park, London SW7 1PU, price £3.75 including postage. Payment should be made with order.

The

M&B May & Baker

Diagnostic Quiz

The answers to the March quiz are as follows:

1. What is the diagnosis?

Aseptic necrosis.

2. What is the most common cause?

Prolonged corticosteroid therapy.

3. What is the treatment?

There is no known medical treatment and spontaneous improvement is extremely rare. The only treatment in the majority of cases is total hip replacement.

The winner of a £100 British Airways travel voucher is Dr S. Krishnaswamy, Whittlesey, Peterborough.