

# Balance of care for the dying between hospitals and the community: perceptions of general practitioners, hospital consultants, community nurses and relatives

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**SUMMARY.** A survey was made of the general practitioners, hospital consultants and community nurses who had cared for a random sample of people dying in 1987. Their views and experiences of the balance of care between hospital and the community are reported. All three groups wanted more people to be looked after in their homes rather than in hospital if adequate care could be arranged at home. But they perceived inadequacies in home help and district nursing services and many wanted other community services expanded or introduced. The main shortcomings of the hospital service were seen as inadequate numbers of hospice beds, difficulty obtaining admission for people needing long term care, discharge too early and some over-treatment of people who were dying. There was some evidence from relatives that pain control was better in hospital than at home, and the district nurses also reported that pain was not controlled satisfactorily for patients dying at home as often as it could be. It is concluded that inadequacies in community services may discourage some people from taking on the care of their relatives at home.

## Introduction

THE balance of care between hospitals and the community is one of the major concerns in the health service and this has been recognized as an issue in the care of the dying for some time. Taylor<sup>1</sup> argued that for the terminally ill, the development of home care services should take priority over further inpatient units. Parkes<sup>2</sup> questioned this on the grounds that, while pain control for cancer patients had improved in the 1970s, severe pain was still common among those who remained at home. Two studies of the last year of life of a random sample of adults who died in 1969<sup>3</sup> and in 1987<sup>4</sup> have shown that, while the proportion of people dying in hospitals increased between 1969 and 1987,<sup>5</sup> admissions were more frequent and stays were shorter in 1987.<sup>6</sup> The 1987 survey sought the views and experiences of three professional groups involved in the care of the dying — general practitioners, hospital consultants and the community nurses. This paper reports their opinions and observations about the balance of care between hospitals and the community, together with some information from relatives and others associated with the people who died. The issues considered here are the appropriateness of the present balance of care, the adequacy of community care and of hospital and hospice services, and pain relief in hospital and at home.

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## Method

The 1987 study was carried out in 10 randomly selected areas of England. A systematic sample of 80 deaths of adults (aged 15 years or more) registered in October or November 1987 were selected in each area.

Interviewers tried to contact the person who could tell them the most about the last 12 months in the lives of these people, and information was obtained about 639 people, 80% of the sample of 800 deaths. Most of the interviews (79%) were with relatives, 10% were with friends or neighbours, and the rest were mainly with staff of residential homes. For convenience, they are all referred to as relatives.

The general practitioners, hospital consultants and community nurses involved in the care of the people who died were identified and approached. Details about these samples are described elsewhere.<sup>4</sup> Questionnaires or interviews were completed by 245 general practitioners (62% of those approached) and 211 hospital consultants (65% response). Among the community nurses the response was higher — 92% of the 100 identified — but only 45% of the nurses reported to have cared for the sample of people who died could be identified. Of the 92 interviewed 85% were district nurses, 2% health visitors, 9% described themselves as specialists in the care of the dying (two thirds of these were MacMillan nurses) and the other four as a stoma specialist, a diabetes nurse specialist, a night sitter auxiliary nurse and a care visitor for the elderly.

Tests of differences in proportions have been applied to the data constantly and have influenced decisions about what differences to present and how much verbal 'weight' to attach to them. Attention is only drawn to differences which are unlikely to have occurred by chance five or more times in 100, unless specifically stated.

## Results

### *Balance of care*

All three groups of professionals were asked whether in their area they would like to see more care for the dying at home (if adequate care could be arranged there), whether more care should be given in a hospital or hospice or whether they felt the balance was about right (Table 1). A majority of both hospital consultants and community nurses wanted to see more care being given in people's homes. General practitioners were more evenly divided between those holding that view and those who felt the present balance was about right.

A list of various hospital and community resources was presented to the three professional groups and they were asked whether they thought more of each of the services were needed in their area (Table 2). Home help services were frequently mentioned by all three groups. General practitioners attached about the same importance to increasing chronic hospital beds. An increase in district nurses services was thought desirable by three quarters of the community nurses and by approximately half of the other two groups.

**Table 1.** Views on balance of care for the dying.

	Percentage of respondents		
	GPs (n=239)	Hospital consultants (n=204)	Community nurses (n=92)
Would like to see more care:			
At home	43	57	59
In hospital or hospice	8	10	5
Balance about right	49	27	33
Other comment	—	5	3
Don't know	—	1	—

n = total number of respondents (excludes six general practitioners (2%) and seven hospital consultants (3%) who did not answer this question).

**Table 2.** Views on further facilities needed in their area.

	Percentage of respondents		
	GPs (n=245)	Hospital consultants (n=198)	Community nurses (n=86)
Chronic hospital beds	66	40	67
Home help services	63	63	87
Geriatric beds	54	38	73
District nurse services	47	54	77
Mental hospital places	43	20	38
Short term general hospital beds	42	50	67
None of these	3	5	—

n = total number of respondents (excludes 13 hospital consultants (6%) and six community nurses (7%) who did not answer this question).

In response to another question, 8% of consultants said that because of the inadequacies of the district nursing service, they frequently had to keep patients in hospital longer than they otherwise would, 42% said they did so occasionally, 47% rarely or never (the rest made other comments). A similar question about the home help service suggested that inadequacies in the service caused rather more problems: 15% of the hospital consultants said they frequently had to keep people in hospital longer, 46% did so occasionally, 35% rarely or never (the remaining 4% made other comments).

### *Adequacy of community care*

The nurses' views on the need for more help services were reinforced by their answers about the adequacy of the home help services in their areas: 36% of them compared with 16% of the general practitioners described them as 'very inadequate'.

Hospital consultants were also asked this question, but a fifth of them said they did not know; among those who did answer the question replies were similar to those of the general practitioners.

All three groups were asked about a number of domiciliary services that might or might not be available in their area and whether they would like to see them introduced or extended (Table 3). One in eight of the consultants said they did not know whether the first three services were available in their area and a further 5% did not answer the question; just over a quarter did not indicate whether they would like these services extended or introduced. These consultants and smaller numbers of general practitioners and community nurses who did not answer the questions have been excluded from Table 3. In addition to the consultants who did not know whether a service was available it would seem that others may have mistakenly believed that a night sitting or night nursing service was not available. More community nurses than general practitioners reported that the various services were available in their areas, except for a day care service for the terminally ill. The nurses were also more likely to want services extended or introduced, especially night sitting services, day care services for the terminally ill and night nursing services.

This desire of the nurses for an increase in night services tied in with their views on the changes they would like to see in the district nursing service or in the way it was organized. Over half of them (55%) wanted to see some changes, compared with two fifths of the general practitioners and a third of the consultants. The most common change the nurses wanted was for more staff, and this was often related to their desire to spend more time with patients:

'If there were more staff we could spend more time with patients and sit and chat if they don't have a caring family and friends.'

The next most frequently mentioned change the nurses wanted was 24 hour cover for patients.

'The problem is that we are essentially a visiting service and can't provide 24 hour care. We can go three times a day but that's not 24 hour care. We need some kind of bank of nurses who, if necessary, could be with the patients 24 hours, and Marie Curie sitters seven nights a week instead of two.'

When relatives were asked for their views one in five felt that it would have been helpful if the general practitioner had visited the person at home either at all or more often. They thought that one in eight of those who had not had any help at home from a district or other type of nurse could have done with some help from a nurse during the year before they died, and just over a fifth, 22%, of those who had had help from a nurse were thought to have needed it more often.

**Table 3.** Availability of community services and views on whether they should be introduced or extended.

	Percentage reporting service available			Percentage who want service extended or introduced		
	GPs	Hospital consultants	Community nurses	GPs	Hospital consultants	Community nurses
Night sitting service	74 (240)	51 (176)	90 (92)	41 (240)	49 (156)	66 (89)
Night nursing service	70 (240)	47 (174)	89 (92)	38 (240)	51 (154)	53 (91)
Day care services for the terminally ill	39 (237)	41 (174)	36 (89)	40 (237)	47 (154)	60 (89)
Geriatric social worker	36 (236)	70 (183)	63 (89)	37 (236)	22 (157)	44 (88)

NB: Figures in brackets are the numbers on which the percentages are based (that is, excluding those who did not know whether service available or did not answer question).

For one third of the people who had died and who had been living alone relatives thought there should have been more help with shopping, cleaning or cooking. This proportion was similar for the 79 patients who had had a home help from the social services (50% of those who lived alone) and those who had not. Among the 365 patients living with others, only 14% had had a home help, and 37% of those with such help were thought to have needed more help with the shopping, cleaning or cooking, compared with only 15% who had not had a home help. So it would seem that those who were living alone were seen as less likely to get such help if they needed it, and that the help they got was felt to be inadequate for one in three of those living alone and for a similar proportion of those living with others.

#### *Adequacy of hospital and hospice services*

General practitioners, hospital consultants and community nurses were all asked about the availability of hospice beds. Three quarters of both groups of doctors and two thirds of the nurses said there were some in their areas. The proportions wanting this service introduced or extended were: 35% of general practitioners, 46% of hospital doctors and 58% of community nurses.

General practitioners were asked whether they found it easy, rather difficult or very difficult to get admission into a suitable NHS institution for a variety of patients. Admission was thought to be easiest in the case of an elderly patient with an acute infection (86% of respondents), but a few (3%) respondents said this was very difficult. The admission of a young patient with a short-term terminal illness was described as easy to obtain by 81% of general practitioners, with 2% reporting it as very difficult, whereas admission of an elderly person with a short term illness was seen as easy by 73% of respondents and very difficult by 6%. The patients who were most often found to be difficult to arrange admission for were an elderly patient needing long term nursing care (17% easy, 29% very difficult) and a young patient with a progressive degenerative condition (18% easy, 28% very difficult).

Relatives and others were asked whether they felt people who had been admitted to hospital during the last year of life had been admitted too soon or too late, and for those who had been discharged, whether this had been done too soon. Nearly a quarter of patients (23%) were thought to have been admitted too late and less than 1% too soon. Eleven per cent were thought to have been discharged too soon or inappropriately.

The issue of possible over-treatment in hospital was raised in a question to general practitioners. Seven per cent thought over-treatment of patients who were terminally ill happened very often, 33% fairly often, 55% occasionally, 4% never (1% made another comment). Some comments related to why or how over-treatment occurred:

'But how can young doctors be expected to take such decisions? Consultants are often not involved!'

Some to the nature of the over-treatment:

'Useless attempts at chemotherapy make patients more ill!'

And others to the characteristics of patients who were over-treated:

'Over-treated patients tend to be younger.'

A few doctors remarked that under-treatment in hospital was more common than over-treatment for patients who were terminally ill.

Relatives were asked whether there was any treatment the person who died should have been given in hospital but was not. They thought this had happened in 8% of hospital episodes (an

episode being one or more admission to the same hospital during the last year of a person's life). One view came from a daughter whose mother aged 76 years had died of cancer of the bladder:

'They should have kept closer tabs on her diabetes. They're so busy with other things, old people don't matter much!'

A similar proportion of relatives (6%) thought that the person who died had been given some unnecessary treatment or operation during a hospital episode and a further 11% were uncertain about this. A daughter whose mother had died of cancer of the bladder said:

'Blood transfusions made her a bit better but prolonged the agony.'

A son who said his mother had died of old age, bed sores and pneumonia said:

'With hindsight, a skin graft [for leg ulcer]. She had to keep still and developed another bed sore. The sister on the ward said the decision to do the skin graft was bad medicine — inadequate communication between consultant and nursing staff.'

Relatives do not necessarily know what should or should not have been done, but their comments suggest that they had not been told or had not understood or accepted what had been done or not done for the person who died and the reasons for this.

#### *Pain control at home and in hospital*

Consultants and general practitioners held similar views about the proportion of dying patients for whom pain could be controlled satisfactorily (Table 4).

**Table 4.** Proportion of cases in which pain in dying patients can be satisfactorily controlled.

	Percentage of respondents	
	GPs (n = 235)	Hospital consultants (n = 203)
All cases	9	14
80-99%	72	72
60-79%	15	12
40-59%	3	1
20-39%	1	—
Less than 20%	—	—
Other comment	—	1

n = total number of respondents (excludes 10 general practitioners (4%) and eight consultants (4%) who did not answer this question).

Community nurses were asked a rather similar question about patients dying at home and about the proportion of patients whose pain was satisfactorily controlled. Like the doctors, most of the nurses (87%) thought it was possible to control pain satisfactorily for 80% or more of patients dying at home. But over a third of them thought it was controlled in a smaller proportion than it could be. A number described the problems of determining the appropriate drug and dose and arranging help when needed. Some ascribed the discrepancy to the reluctance of patients to take drugs. Others were critical of general practitioners or felt there was a more widespread lack of knowledge:

'A lot of GPs tend to stick to dosages they know, and they are reluctant to increase them. It's not like being in hospital with consultants always available!'

Inadequate liaison was also blamed and a few nurses mentioned more than one cause:

'Sometimes a patient denies pain and says he's pain free and sometimes GPs are not aware of pain and not giving enough analgesics.'

Relatives and others who answered questions about people's lives in the year before death may have been more aware of any shortcomings in the care provided at home than of what happened in hospital. Certainly more of the relatives were unable to answer the question about pain relief in hospital than pain relief at home (17% versus 11%). But the observations and opinions of those who were able to answer the questions suggested that pain was more likely to be treated in hospital than at home (for the 408 people with pain reported at home, 342 in hospital, 96% compared with 91%) and that the hospital treatment was more effective. Nineteen per cent thought that when pain was treated in hospital it was relieved completely all the time, whereas the corresponding proportion for pain treated at home was 9%, and the proportions saying the treatment did not relieve the pain at all was 3% for hospital care, 10% for care at home.

### Discussion

The response rates from two of the three professional groups surveyed were only 62% and 65% respectively for general practitioners and consultants. Those who were less interested in the care of the dying may have been less likely to participate. Another point of concern is that so many of the consultants, between one in eight and one in five, said they did not know about the availability of various community services in their area, and as many as one in four did not answer questions about whether or not they would like these services introduced or extended. Indeed the lack of knowledge, and apparent apathy, of some consultants about community care can be seen as an important finding of this study as it is likely to affect attempts to change the balance of care between hospital and community.

Few, 10% or less, of each of the three professional groups wanted to see more care for the dying given in hospitals or hospices. In contrast, between two and three fifths would have liked to see more of this care given in people's homes — if it could be done adequately. But it is clear from their replies to other questions and from the views and experiences of the relatives of people who died that more resources are needed in the community if this is to be achieved. In particular more home helps, more district nurses and more night nursing and night sitting services are called for. In addition, it has been reported that one in five relatives in this survey felt that it would have been helpful if the general practitioner had visited the person at home either at all or more often.<sup>7</sup>

Community nurses reported that pain was not controlled satisfactorily for patients dying at home as often as it could be, and there was some evidence from relatives that pain control was better in hospital than at home. Some people may be willing to accept rather more pain or delays in pain relief for the other comforts and advantages of remaining in their own home. That said, it is obviously important and desirable that distressing pain, particularly in patients who are dying, should be relieved as effectively and quickly as possible. Findings about inadequate pain control at home are supported by the observation reported in an earlier paper that rather more than half the general practitioners (54%) indicated that it would be helpful to have more training in the management of pain.<sup>7</sup> With the rapid developments in the techniques of pain control such further education is likely to be an ongoing need. This in turn demands the participation of consultants who are specialists in this field, and they need to be aware of services outside the hospital.

It may well be that the absence of adequate supporting services in the community makes some people reluctant to take on the task of caring for their relatives, realizing that if they do they will have to take on more responsibility than could be

regarded as reasonable. If that is so, the clear inadequacy of so many of the community services may jeopardize what has been up to now the most important source of care and support for people in the community during the last 12 months of their lives.<sup>3,8</sup> And that in turn will put further demands on the hospital service and lead to the balance of care being tipped in an unsatisfactory direction.

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All Faculties of the College are being given the opportunity to administer the project in their area. The project is scheduled for commencement in January 1992. Members or Fellows of the College with a special interest in palliative care who would be interested in participating in the project, should contact their local Faculty Honorary Secretary in the first instance. Further information and details about the project are available from Mr A Singleton, Clinical and Research Division, RCGP, 14 Princes Gate, Hyde Park, London SW7. Closing date for applications: 30 September 1991.