The role of the general practitioner in caring for people in the last year of their lives

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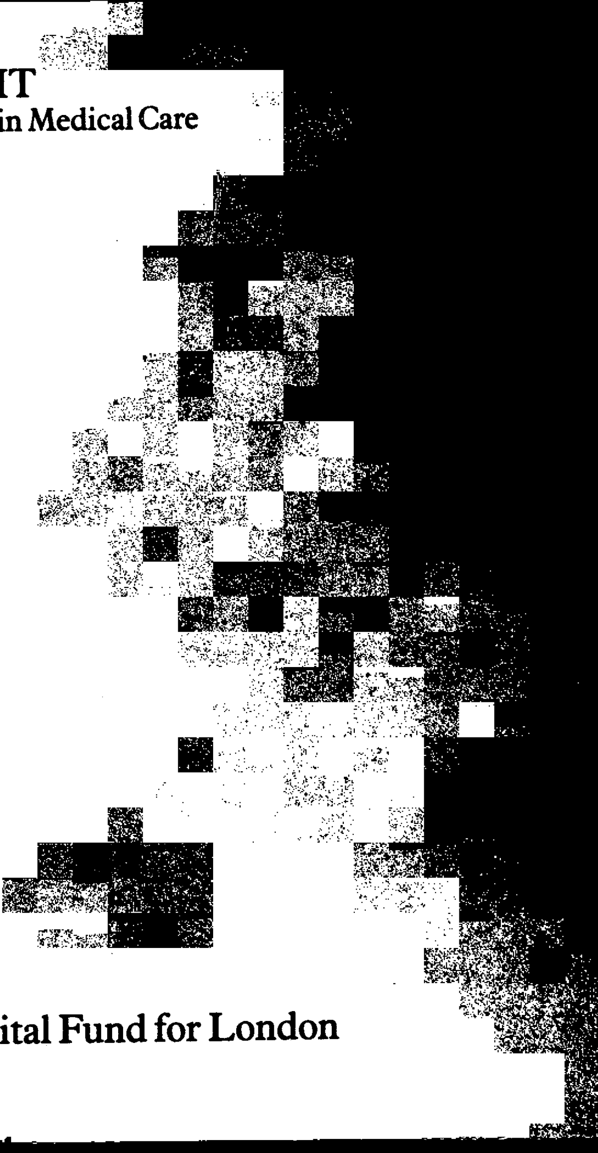

King Edward's Hospital Fund for London

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Summary

The care given to a random sample of adults who died in 1987 is described retrospectively by relatives and others who had known them. Most praised, or were satisfied with, the care given by general practitioners but both the statistics and the quotations reveal some disconcerting inadequacies in this care, particularly over home visiting. This was much appreciated when it happened, but had declined markedly since a similar study in 1969.

The views and experiences of the general practitioners who had cared for the people who died were also sought. Many of them, particularly those in practices with large average list sizes, would have liked to be able to give more time to people who were dying. And those with larger lists had visited the people in the sample less frequently.

It is suggested that this approach, of taking a sample of deaths and looking at the care given in the period before death, is a useful way to audit general practice care.

Introduction

Although the majority of people (two-thirds) now die in a hospital or other institution (OPCS 1989) few spend the whole of the last year of their lives in hospital; most are under the care of their general practitioner for a large part of this time. This paper is about the care people get from their general practitioners during the twelve months before they die, the views and assessments by their relatives and others of the quality of this care and about the views of general practitioners on caring for people who are dying. It also looks at the way this care varies with the characteristics of the patient, the illness and the doctor.

Methods

The study is based on a random sample of adult (aged 15 or more) deaths registered in ten areas of England in October and November 1987. Interviewers tried to contact the person who could tell them the most about the last twelve months in the lives of these people, and information was obtained about 639 of the deaths, 80% of the initial sample of 800. A husband or wife was interviewed about just over a third, a son or daughter about a quarter, other relatives about a sixth, friends and neighbours about a tenth and an official, mostly staff in residential homes, about a tenth. Fourteen of the 639 had spent all the last year of their lives in hospital. The general practitioners of 88% of the others were identified adequately enough for us to send them a postal questionnaire. There were 397 of them as some people in the sample had the same doctor. Some basic information about most of these doctors was available from the Department of Health and from the Medical Register. In addition 62% completed a postal questionnaire about their experiences and attitudes in caring for the dying. For further details about the sample and the methods see Cartwright and Seale (1990). This shows that younger doctors were more likely to respond than older ones, more of those who trained in Great Britain replied than those who trained elsewhere and trainers more than non-trainers. But no differences in response rates were found in relation to the number of visits they made to the people who died, nor in relation to the respondents' assessments of the care that they gave.

Frequency and nature of consultations

During the last year of their lives people tend to have several contacts with their general practitioners. The estimated numbers are based on information from the people we interviewed. Some of these respondents, one in eight, felt unable to make any estimate and for others it may have been difficult for them to make accurate assessments. In addition, they may not have been aware of all the consultations that occurred. Excluding the few who spent all the year in hospital and those for whom no information was available, the estimated average was just under ten consultations and this rose to ten-and-a-half if

Table 1 Contacts with general practitioners in the last year of life

All consultations	%
0	5
1	3
2–4	28
5–9	22
10–19	23
20 or more	19
Estimated average	9.8
Home visits	%
0	20
1	9
2–4	27
5–9	17
10–19	15
20 or more	12
Estimated average	6.8
Night calls	%
0	73
1	12
2–4	11
5–9	2
10–19	1
20 or more	1
Estimated average	0.9
Number of people excluding those in hospital all year (= 100%)*	625

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* Those for whom inadequate information was obtained have been included in the total but excluded when calculating percentages.

sudden deaths with no illness or warning or time for care were excluded. The distribution for all consultations and for home visits and night calls are shown in Table 1.

A relatively high proportion of the contacts, about two-thirds, were home visits and roughly a tenth were night calls. Even so, one in five did not have any home visits during this time and the majority, nearly three-quarters, had no night calls. Among people dying at home and those dying in hospital the number of consultations were similar* but those dying in hospices (4% of the sample) were more likely to have had 20 or more consultations with their general practitioners, 36% compared with 19% of those dying at home or in hospital. This reflects the greater contact that people dying of cancer had with their doctors, compared with those dying of other conditions (Seale in draft a).

The numbers of home visits were less than among those in a similar study almost 20 years ago (Cartwright, Hockey and Anderson 1973 and Cartwright in draft). On the earlier study 30% of the people who died in their own home had less than five home visits, on this study that proportion had doubled. This reduction in home visiting has happened even though people were dying at an older age on the more recent study and home visits increased with age. This is shown in Table 2.

Table 2 Variation in the number of home visits and night calls with age

Age at death	*Estimated average number of* home visits *in last year*	*Estimated average number of* night calls *in last year*	Number of deaths on which average based
Under 55	5.3	1.3	57
55–64	4.9	1.1	72
65–74	5.9	0.8	137
75–84	6.9	0.8	169
85 and over	9.5	0.6	119

There is a clear trend with age apart from those dying under 55, a relatively high proportion of whom died from cancer (37% compared with 25% of older people). In spite of their comparative youth those dying from cancer had an estimated average of 8.5 home visits compared with 6.1 for those dying of other causes. By contrast, those dying of ischaemic heart disease had a lower than average number of

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* In general, attention is not drawn to differences which might have occurred by chance five or more times in 100.

home visits: 5.2, but several of these deaths were sudden ones with no previous illness or time for care: 18% compared with 5% of deaths from other causes. Cancer patients also had more night calls than other patients: 1.4 compared with 0.6, but night calls seemed to decline with increasing age (See Table 2).

People who lived alone had fewer consultations than those who lived with others: 8.1 compared with 10.2. But the difference in the average total consultation rate between the single, 8.6, and the married or previously married – for both of which it was 10.0 – did not reach statistical significance, although the RCGP/OPCS/DHSS (1990) study found that adults who were single consulted less frequently than those who were married, widowed or divorced. That study also found that people living in council housing were more likely to consult than those in owner-occupied housing. This study found no differences between owner occupiers and council tenants (a possible index of social class) in the number or place of their consultations with general practitioners. The earlier, 1969 study, (Cartwright, Hockey and Anderson 1973) also found no social class variations in the number of general practitioner consultations, home visits or night calls and concluded that 'death in many respects appeared to be the equaliser it is so often reputed to be.' More surprisingly, men and women did not differ significantly in the total number of consultations reported but women had more home visits than men: 8.0 against 5.5 – a reflection of the older age of women at the time of their death.

Most, 73%, of the people who died who consulted a general practitioner at all saw only one or two different general practitioners (including partners, locums or deputies) in the last twelve months of their lives; 25% saw three or four and 2% five or more. For those seeing more than one, 16% of the respondents felt it would have been better to have fewer doctors, and this proportion was 25% if the person had seen more than two doctors.

> A son whose father had seen five or more doctors said: 'When you have one doctor for one patient it must be better. They know the case better and can see if the person is improving or not. Each doctor has their own ideas and so they start to argue with one another about what to do. They all think different.'

Respondents' views of general practitioners' care

Most of the people we interviewed who could answer our questions about the care the person who died got from their general practitioners* described that care positively: 87% thought the doctor was an easy person to talk to, 82% that he or she had time to discuss things, 83% felt the way the doctor looked after the person who died was very (63%) or fairly (20%) understanding and 74% described the care the person who died got from his or her general practitioners in the last year of life as excellent (41%) or good (33%). On the obverse side there were criticisms. One in ten thought the doctor was not an easy person to talk to.

> 'Not easy at all. More of the old school. You tell him what is wrong and he gives you something, but no explanation. Sort of "I know best". I think he probably thought we couldn't cope with knowing Dad was dying. But it was the very thing we needed to know. I think he's frightened of telling you how it is. When we were desperate and tried to get it from him he just wouldn't communicate.' (Son)

Fourteen per cent thought the doctor did not have time to discuss things:

> 'They always seem to be in such a tearing hurry.' (Wife)

> 'He explained at first, then seemed to tire of her. My mother found her illness (Parkinson's disease) difficult to accept and probably kept asking the same things.' (Daughter)

Eight per cent felt the general practitioner was 'not very understanding'.

> A husband whose wife had died of cancer described the three doctors his wife had seen as easy to talk to and said they had time to discuss things but felt they were 'not caring – technicians rather

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* We did not ask these questions about the few (5%) people who died suddenly when they were under 65 and we only asked respondents who had the same doctor as the person who died (51%) and others who knew the doctor (27%) about whether they thought the doctor was an easy person to talk to and had time to discuss things.

> than doctors – you get a tablet and that's that – they're not interested.'

And 7% described the general practitioner's care of the person who died as 'poor'.

> The sister of a woman who died of heart failure described the care her sister got from her general practitioner as 'awful: the doctor neglected her. He did nothing, showed no interest. He wouldn't come to see her. Once she went to the surgery, early last year. It took her four hours to walk there and back, then she had to wait over an hour to see him at the surgery. He showed no understanding at all, no interest. All he did was write a prescription. He didn't examine her. She wasn't fit. When I sent for him he said he didn't do home visits and she should go to see him. I told him she wasn't well enough, that was when he wrote to her, telling her to go to see the specialist. She just wasn't well enough to go. When she was really ill at the end the home help sent for me. When I got there she was so ill I rang the doctor. He wouldn't come. Then the home help rang him. He still wouldn't come. Then we got hold of the supervisor from the home help service. She came and immediately rang the doctor. She said if he didn't come she would ring the police doctor. He finally came. When he saw her he couldn't get to the 'phone quick enough to 'phone for the ambulance. It was too late, of course. She died later (within a week) in hospital. I have complained to the Family Practitioner Committee but they wrote to say I had to make a formal complaint and go to see them. I am so upset about it and at my age I get so distressed I didn't feel I could go through with it.' (Sister aged between 65 and 74)

That example includes complaints that were made by a number of people – failure to examine and writing prescriptions rather than doing things. It also highlights the most frequent criticism which was over home visiting. Fourteen per cent thought the doctors were rather reluctant to visit and 21% felt it would have been helpful if the doctor had visited the person who died at home – either at all or more often. They made this last criticism more often when the person lived alone than when he or she was living with others (29% compared with 19%) and as stated earlier, people living alone had fewer home visits.

Respondents' summing up of the different aspects of care the people who died got from their general practitioner was strongly related to the number of home visits they had had: the proportion describing the care as fair or poor (rather than excellent or good) was 28% for those who had had less than five home visits in the year before they died, 16% for those with five to nine home visits and 5% for those with ten or more.

When the doctor had visited 20 or more times few respondents, 8%, thought he or she should have done so more often. This proportion rose with the declining number of home visits to 33% for those who had between two and four visits, but fell again to 19% for those with none or one – presumably because those people were generally felt – by both doctors and relatives – not to need such care.

For most of the people for whom it was felt that it would have been helpful if the doctor had visited at all or more often, the doctor had not been asked. But for 16% this had happened, and the doctor had not come.

> 'He felt he couldn't do any more for her. He once said he didn't like dealing with old people.' (Daughter whose mother had Parkinson's disease)
>
> 'He said there was no point on a couple of occasions – he could not help her. He seemed to lose patience with her as she got worse. At first he thought it was Alzheimer's disease because she was quite rational at times. But as time went on she became more and more confused and he seemed to get annoyed because she got people to contact him. He didn't seem to realise just how it was affecting us. We didn't know sometimes if we were coming or going. She needed to be constantly watched.' (Daughter)
>
> One patient was clearly difficult. His son-in-law told us that 'He'd assaulted the doctor and the doctor was very reluctant to see him. He would not let them look after him.'
>
> A wife whose husband had had an operation for bladder trouble in the year before he died said: 'You felt that if at all possible you had to go to the surgery. The receptionist made if difficult when you called to ask them to come out. They asked lots of questions. In the end, couldn't be bothered, went to surgery.' Then when 'he took bad one night with pains in the chest it took two-and-a-half hours

> to get the doctor to call. He sent for the ambulance. He was taken to hospital and put on a machine in intensive care.' But he died of a heart attack.

A daughter who said the doctors had come when asked and described her mother's doctors as willing to do home visits qualified this by saying:

> 'They would come out when you asked them but they never followed the visits up.' She felt it would have been helpful if they had visited her mother more often 'They would have seen the change in her – that she was getting worse . . . She had had sickness and diarrhoea for about four months. The doctor just gave her medicine and said she was O.K. They looked at her and said it was nothing nasty.' (Died of cancer of the liver)

> Another daughter who felt it would have been helpful if the general practitioner had visited her mother said he was not asked because her 'mother was satisfied to talk to the receptionist and did not push the doctors to call. She would call the doctor and speak to the receptionist who would ask her what was wrong and what she wanted and send a prescription. (She took paracetamol all the time) You don't seem to be able to get a doctor out of his surgery now, especially old people, they are not forceful enough to ask to see the doctor, they just accept what the receptionist says. My mother was always saying how thoughtful the receptionist was when she called, and always asked her how she was, but that didn't get the doctor out to see her.' The daughter felt that 'if my mother had been seen regularly then the deterioration might have been noticed.' Her mother only saw a general practitioner once in the year before she died and that was the emergency doctor whom her brother called and who admitted her to hospital where she died within three days of pulmonary oedema, acute left ventricular failure, macrocytic anaemia and myocardial degeneration, and acute lung abscess. The death was certified by the coroner after a post mortem.

While the most frequent criticism was about reluctance or failure to visit, some of the most bitter comments seemed to be related to what was seen as failure to diagnose a problem early enough.

> The mother of a young (35–44) woman who died of cancer told us that her daughter had complained of various pains for nine months but the doctor said nothing was wrong with her. The daughter consulted her general practitioner at least ten times in the year before she died and had one home visit. The mother described they way the doctor looked after her as: 'Neglect. He's an old man and kept telling her she looked too well to be ill. He gave her all sorts of pills for stomach and back pains. Then she collapsed at work and they took her to the hospital and the young doctor who saw her was horrified. They did all sorts of tests and found she was full of cancer. If it had been diagnosed at the beginning they might have saved her.'
>
> A wife whose husband died of Hodgkin's disease, aged 35–44, also felt it might have been cured if it had been caught early enough. As it was 'the disease went into his spine and that left him paralysed.' Later he 'lost bladder and bowel control, then finally his kidneys packed up and that was it.' He also had rheumatoid arthritis. He'd had 100 or more visits from a nurse in the last twelve months of his life but saw the doctor 'hardly at all' – between two and four times. The wife described the care from his general practitioner as 'bad, very bad. He (the doctor) just never seemed interested, very abrupt. He's weird, even the district nurse thinks that. It always seems as if he's in a hurry – everything has to be quick. It's just the reaction you get from him. He's talking to you and going out of the door at the same time.'

Even if these relatives were mistaken in thinking that earlier diagnosis and intervention would have prevented the death of their daughter or husband, it is clear that they did not get the support they wanted from the general practitioner while caring for their dying relative.

The last two illustrations might suggest that respondents were more likely to be critical of general practitioners over the care given to young people who died, but this was not so. Nor were there any notable differences with cause or place of death, or with our index of social class (housing tenure) except that for owner occupiers the doctor was more often regarded as not easy to talk to: 14% compared with 7% for council tenants. It may be that owner occupiers had high expections but an alternative explanation is that doctors are less relaxed, or less approachable with people they perceive as nearer their own status. Apart from those already mentioned over visiting there were no other differences in respondents' assessments of the care given to those who lived alone and those living with others.

Praise was more common than criticism, and there were many descriptions of caring doctors and comments which indicate the things they appreciated about the way the doctor looked after the person who died. Visiting was clearly valued.

> 'They came whenever we rang and said they would come any time, even if only for reassurance for mother.' (Son)

> 'When Tom wouldn't go to see him, I went and had a quiet word with him. Tom was so stubborn, he didn't like bothering the doctor, but he (doctor) said he would call just to see how he was. He did and it was a great help to us.' (Wife)

So were explanations and the time spent in giving these.

> 'He always takes time to explain and to be as helpful as he can be. He was so considerate at the time – and since. Nothing is too much trouble for him. He told me what to expect and he was right. We couldn't have wished for better help and care. My husband had faith in him.' (Wife whose husband died of cancer of the stomach)

> 'He's very easy to talk to. He is my type of doctor – straightforward. He takes time to explain what is wrong, how he is treating it, with what and why. He explained what was wrong with Harry. He said I must keep calm, try not to get too upset and to call him if I needed him.' (Wife whose husband died of cancer)

People were grateful when doctors made arrangements for other types of care.

> 'To me he is like a brother. He talks sensibly and explains everything. When my mother started to be ill he said "You can't carry on like this." He got help during the day and I paid for help at night. Then he told me she was getting worse and really we must get her into a home. He said it was the best place for her. He arranged for the health visitor to come and take me to see the place.' This daughter described the care as '100% – couldn't have

> been better.' (Daughter whose mother had senile dementia and then a stroke)

Other favourable comments were:

> 'She always said he was good doctor and that she could talk to him. He sent her for the tests and things and came to see her regularly here.' (Friend)

> 'My husband didn't want to go into hospital for the hernia. The doctor was kind and persuaded him. He knew how upset he was about having to go into hospital again.'

And kindness and sympathy at the time of death were recalled with gratitude.

> 'He put his arm round my shoulder. I said it still hurts, even though we were expecting it. He understood because he had lost a child himself not long before.' (Son)

Lack of feeling at this time was occasionally recalled, but with resentment.

> 'When my father died he saw father and said "Sorry Mrs ------ (mother), he's left us." That was all. I've never seen him since.' This daughter said a locum came subsequently when she asked a doctor to come to see her mother. The locum was 'a lady who let her talk and stroked her head and was sweet in herself.'

A general practitioner was present at 5% of the deaths that occurred at home and came to the home within an hour of another 61%. More information about the care and support given by doctors and others to the bereaved is given in another paper (Seale in press).

Although many more respondents made appreciative rather than critical comments about the general practitioner's care, sometimes the lack of criticism alongside the description of what happened seemed surprising.

> A daughter who described the care her mother had from the general practitioners as 'reasonable' went on to say 'If only he had taken more notice of her that Monday before she died he might

have been able to do something for her. But he didn't give her a good examination. He just said she had wind and the pain in her chest was indigestion.' Her mother died of congestive cardiac failure on the Thursday that week.

> Another daughter who described her mother's doctor as easy to talk to went on to say 'You can always ask her things, it's just that she only gave half answers.'

> A wife whose husband had a stroke seven years before he died of a massive heart attack at home and who had needed help with nearly all aspects of personal care since his stroke had not been visited at all by a doctor in the year before he died. But she blamed herself: 'If I'm honest he should have seen the doctor more often. My fault really.' She'd taken him to the surgery two – four times, but felt it would have been helpful if they'd visited him at home as 'he used to get a bit worked up going to the surgery.' But she hadn't asked them to come because she thought 'it wasn't fair to trail them out.' She described the care he got from the general practitioners as 'good' but commented 'I sometimes think if they'd taken his blood pressure more often . . . but they didn't.'

Several informants commented on the unwillingness of the person who died to consult or 'bother the doctor' or ask for a visit.

> A wife whose husband had 'started with blackouts about three years before' he died, described the care he got from his general practitioners as excellent and said 'If we asked them they were always here straight away and did what they could.' But 'they could not visit if he would not have them in.' I would say many times let me call the doctor when he had his blackouts but he said "no, it will go away soon." He did not like doctors and did not like to bother them.' (Died of cerebral infarction)

> Another wife whose husband had been ill with schizophrenia for 15 years and who hanged himself said: 'They did all they could. He did not like to see doctors often, he had enough of them when he was in hospital.' She described the general practitioner's care as 'Very good. There wasn't much they could do. He was beyond them.'

> A husband related how 'I had always promised her I would not call the doctor unless she asked me to. We promised each other this years ago. At first she would not let me call him, but eventually she did.' He described the care his wife got from the general practitioners as 'very good. They, like me, just didn't realise how ill she was because she didn't complain and she was so strong willed she could cover up her pain and appear all right. The doctor came four times in ten days and the last time said she had to go into hospital. They took her in and did x-rays and found she had lung cancer.'

Some people seem reluctant to criticise doctors and others may not want to admit to themselves that their relative could have had better care in the time before he or she died. What did the general practitioners themselves feel about caring for patients who were dying?

General practitioners' perspectives

Just over half, 56%, the general practitioners who answered our questions felt that on the whole they were able to give enough time to patients who were dying, but 43% felt they would like to give more time, with 1% making other comments.

Younger doctors, aged less than 45, were more likely to feel they would like to give more time to dying patients: 48% compared with 34% for older doctors. (This proportion was high, 64%, among the 28 doctors who responded to the questionnaires but who could not be traced in the Department of Health files or whose name was not recorded there.) More of the doctors who reported that they had been through a recognised vocational training scheme for general practice would like to have more time for this group of patients: 53% against 35% without such training. Of course, vocational training is strongly related to age: 20% of those aged 45 or more had been on a recognised vocational training scheme, 70% of the younger doctors. A three-way analysis showed it was the younger doctors who had had a vocational training who differed from the others, 54% of them wanted to spend more time with the dying, 34% of the others – with no variation between the other three groups.

Doctors working in practices where the average list size was 2,500 or more (this information came from the Department of Health) more often felt they wanted to give more time to patients who were dying: 55% compared with 36% of those with smaller list sizes. Another characteristic which distinguished the two groups was wanting further training in different aspects of terminal care. The figures are in Table 3 and show that more than half the general practitioners wanted further training in three of the various aspects of terminal care asked about, and two-thirds wanted further training in bereavement counselling. Haines and Booroff (1986) reported similar findings.

Table 3 Proportion of general practitioners wanting more training in various aspects of terminal care by whether or not they would like to be able to give more time to patients who are dying

	General practitioners who		
Proportion who would find it helpful to have further training in:	Feel able to give enough time	Would like to be able to give more time	All general practitioners
	to patients who are dying		
Management of pain	48%	64%	54%
Control of dyspnoea	51%	64%	56%
Relief of nausea and vomiting	41%	58%	48%
Communication with dying patients	50%	66%	56%
Bereavement counselling	57%	76%	65%
Number of doctors (= 100%)*	133	103	245

* Small numbers for whom inadequate information was obtained have been excluded when calculating percentages but are included in the base numbers.

The question about wanting to spend more time with dying patients was not related to being a trainer or member or fellow of the Royal College of General Practitioners. It was similar for men and women doctors, for those who trained in Great Britain or Asia and did not vary with their practice involvement in vocational training or teaching of medical students. Possibly, given the relationships with wanting further training in terminal care, this question has identified doctors with a particular interest in, or concern for, people who are dying. If so, one might expect this to be reflected in the reports of our respondents about the care given to the people who died. But no differences emerged either in the views of the respondents about the care that was given or in the number of consultations and home visits reported for the patients of the two groups.

General practitioners were asked how easy or difficult they found it to cope with their own emotional reactions to death and dying. Just under two-thirds said they found it easy (13%) or fairly easy (52%) and a third difficult (3%) or rather difficult (30%), with 2% making other comments. (Nearly all this last group indicated that it was between fairly easy and rather difficult.) They were also asked how easy or difficult they found it to cope with the emotional distress of terminally ill patients and their relatives. Rather more, almost half, found this difficult (5%) or rather difficult (44%). Responses to the two questions were strongly related: just over a third, 37%, of those who found it easy or fairly easy to cope with their own emotions said they found it difficult or fairly difficult to deal with the distress of patients compared with almost three-quarters, 74%, of those who found it difficult or rather difficult to deal with their own reactions. Neither assessment varied significantly with the doctor's sex, country of qualification, whether he or she was a trainer or member of the Royal College of General Practitioners, nor was there any clear trend with the doctor's age in the doctor's ability to cope with their own reactions, but younger doctors reported more difficulty dealing with the emotions of patients or relatives: 57% of those aged 45 or less said they found this difficult or rather difficult compared with 39% of older doctors. Those with larger lists of 2,500 or more, were more likely to say they found it easy to cope with their own emotions: 23% compared with 10% of those with smaller lists. And 59% of those with large lists compared with 46% of those with smaller ones found it easy or fairly easy to deal with reactions of patients and relatives.

There was no difference in the number of home visits made by doctors who found it easy or difficult to cope with either their own emotional reactions or those of their patients and relatives.

Respondents' assessments of the general practitioners' approachability and understanding were related to the doctors' assessments of their abilities to cope with their own emotions but not to their views on how easy or difficult they found it to cope with the distress of patients and relatives. More of the doctors who found it easy to cope with their own feelings were described as being easy to talk to: 97% against 83% of the others; and more of those who found it difficult or rather difficult to cope with their rections were said not to have time to discuss things, 21% compared with 11% of those finding it easy or fairly easy. Fewer of those finding it at all difficult were described as having looked after the person who died in a way that was 'very understanding' 57% compared with 68% of those who found it easier. It would seem as if the question about their own reactions has identified some doctors who have some problems in communicating with patients who are dying or with their relatives and do not respond to their needs so effectively.

There was a clear trend in responses to this question and the doctors' wishes for more training over various aspects of care. This is shown in Table 4.

Table 4 Relationship between doctors' own emotional reactions to death and dying and views on further training

	Proportion thinking further training would be helpful		
	Ability to cope with own emotional reactions to death and dying		
Would find it helpful to have more training in:	Easy	Fairly easy	Rather difficult or difficult
Management of pain	34%	51%	68%
Control of dyspnoea	34%	61%	58%
Relief of nausea and vomiting	28%	47%	57%
Communication with dying patients	31%	55%	69%
Bereavement counselling	34%	66%	77%
Number of general practitioners (= 100%)	30	125	79

Doctors who said they had some difficulty coping with the emotional distress of terminally ill patients and their relatives were more likely than those who found it easy or fairly easy to want more training in communication with dying patients; 66% against 47%, and more training in bereavement counselling; 75% against 55%; but they were no more or less likely to want training in symptom relief.

But whether such training would improve doctors' ability to cope with their own or their patients' reactions is uncertain. There was no difference between those who said they had had some specific training in the care of the dying or management of bereavement and those who had not in their statements about their ability to cope with their own emotional reactions or with those of terminally ill patients and their relatives. And if such training was readily available it did not seem as if those in most need of it would be more likely to enrol for it than others; among those who thought it would be helpful to have more training in communication with dying patients the proportion who were described as being easy to talk to was 87% compared with 82% among those who did not think it would be helpful – a difference which might well occur by chance, but there were no differences significant or otherwise in the opposite direction.

It may be that what doctors with difficulty in coping with distress need is help in understanding their own emotions rather than training in communication skills.

Relationship of general practitioner characteristics and the care given to patients who died

It might be expected that general practitioners who had had some *specific training in the care of the dying or management of the bereaved* would be more skilled or understanding in their care. A quarter of the general practitioners who answered our questions reported such training. This was more common among members or fellows of the Royal College of General Practitioners, 41% of whom had such training compared with 21% of non members, but there was no difference between those with such training in the views of respondents on the care given to the people who died nor in the number of consultations and home visits reported.

Table 5 Estimated number of home visits and other consultations for patients of doctors with different list sizes

	Estimated number of			Number of people who died
	home visits	surgery consultations	all consultations	
Average list size	during 12 months before death			
Under 1500	9.4	2.9	12.3	24
1500–1999	7.8	2.8	10.6	132
2000–2499	6.3	3.1	9.4	184
2500 or more	6.6	3.2	9.8	106

The frequency of home visiting did however appear to be related to the *average list size* of the general practitioner. The estimated numbers of home visits and other consultations are shown in Table 5; the main difference is for people with doctors in practices with an average list of less than 2,000 (who had an estimated average of 8.0 home visits in the year before they died) and those whose doctors looked after 2,000 or more patients (an average of 6.4 home visits).

But our respondents did not regard doctors with larger lists as being more reluctant to visit nor were they more likely to say it would have been helpful if the doctor had visited the person who died more often. Those with larger lists may select their home visits more carefully and effectively than those with fewer patients to care for. There were no other significant differences in our respondents' assessments of the care given to the person who died with their doctor's list size.

The *doctor's age* was related to some of these assessments (see Table 6) with younger doctors coming out rather better in terms of being easy to talk to, having time to discuss things, being understanding in the way they looked after the person who died and giving them excellent care. This ties in with indications from other studies (Cartwright and Smith 1988, and Bowling and Cartwright 1982) that elderly patients may have a more satisfactory relationship with younger than with older general practitioners. But unlike the other studies there was no evidence on this one of lower consultation or home visiting rates for people with older doctors.

In the assessments, general practitioners in their forties tended to attract rather more criticisms than either younger or older general practitioners, but this difference only reached statistical significance over not being easy to talk to. Doctors in their late forties had larger lists than others: 40% of them were in practices with average list sizes of 2,500 or more compared with 21% of doctors aged 50 or more and 23% of doctors under 45, but, as stated earlier, list size was not related to these assessments.

The proportion of *women doctors* fell from 24% among those under 40, to 15% of those in their forties and 6% of those aged 50 or more. And it seemed that women, like the younger doctors, were regarded as easier to talk to (92% compared with 86% of men) and to have more time to discuss things (86% against 80%), but neither of these differences was statistically significant.

Vocational training too was more common among the younger doctors: 78% of those under 40 said they had been through a recognised vocational training scheme for general practice, 35% of those in their forties, 14% of those in their fifties but rising again to 38% of those aged 60 or more. Those who had been trained under such a scheme were more often regarded as easy to talk to (92% compared with 78%) and their care of the person who died was less likely to be described as not very understanding (5% against 11%) or as 'fair' or 'poor' (14%

compared with 26%). The difference in the proportion categorized as reluctant to visit, 9% against 17%, did not quite reach significance and the number of home visits reported for patients of the doctors in the two groups was similar. An analysis confined to doctors aged 40 or more showed that the differences between the vocationally trained and the others remained and could not be just attributed to their age.

Nineteen per cent of the general practitioners were recorded in the Medical Register as being *members or fellows of the Royal College of*

Table 6 Variation with doctor's age in respondents' assessments of the doctor and his or her care

	Doctor's age						
	Under 35	35–39	40–44	45–49	50–54	55–59	60 or more
Doctor described as:	%	%	%	%	%	%	%
easy to talk to	98	92	76	76	88	84	91
not easy	2	5	22	22	10	12	7
other comment	–	3	2	2	2	4	2
Doctor thought to have:	%	%	%	%	%	%	%
time to discuss things	94	81	77	73	80	79	82
not	6	14	20	20	17	16	11
other comment	–	5	3	7	3	5	7
Respondent described the way the doctor looked after the person who died as:	%	%	%	%	%	%	%
very understanding	71	70	55	60	61	68	64
fairly understanding	19	19	24	19	21	18	20
not very understanding	–	5	10	13	11	9	6
other comment	10	6	11	8	7	5	10
Respondent thought the different aspects of care the person who died got from their general practitioner was:	%	%	%	%	%	%	%
excellent	52	48	36	44	36	42	35
good	32	32	33	26	39	33	35
fair	8	17	13	10	11	12	14
poor	3	3	8	14	9	6	8
no care	3	–	8	4	4	5	6
other comment	2	–	2	2	1	2	2
Number of people who died*	61	91	68	52	77	89	53

* People who spent all the last year of their lives in hospital and those for whom respondents did not make any assessments have been excluded when calculating percentages.

General Practitioners. There was no clear trend in this proportion with age or list size and the proportion was similar for men and women doctors. The care given to patients of College members was rated as excellent or good in 82% of instances compared with 73% of patients of non-members, a difference which fell just short of statistical significance, and there were no differences in reported care which reached it, although 27% of College members were trainers compared with only 5% of non members and it might be thought that trainers might be more highly rated by our respondents than other doctors but, as will be shown next, the only observed difference was in the opposite direction.

Ten per cent of the general practitioners in our sample were classified by the Department of Health as *trainers*, and the only significant difference between them and the others in our respondents' assessments was that more of the care given by trainers was described as not very understanding: 16% compared with 7% for other doctors. Possibly patients of doctors who were trainers were more often seen by trainees, locums or assistants. Certainly a relatively high proportion of the respondents for people whose doctor was a trainer felt it would have been better if they had seen fewer doctors: 32% compared with 16% of those who were not trainers, although the number of different doctors seen did not differ appreciably between the two groups (the average numbers were 2.3 and 2.1).

Comparisons were also made between doctors in the *north and those south* of the Bristol–Wash line. There was no significant difference in the number of reported consultations and home visits nor in our respondents' assessments of care but more of the general practitioners in the south were in practices where the average list size was 2,500 or more: 32% compared with 18% in the north, and more of the doctors in the north qualified in Asia: 23% against 9% in the south.

An analysis by doctors in *inner city areas, other metropolitan areas and county boroughs* also showed no differences in the number of home visits or in respondents' assessments of care except that, in the county boroughs, doctors were more often thought not to have time to discuss things – by 18% of the respondents compared with 10% in other areas. Possibly people in county boroughs have higher expectations about this. Doctors in inner city areas tended to fall at the two extremes in relation to list size: 49% of them compared with 36% of other doctors had average list sizes under 2,000 and 10% compared with 2% had lists of 3,000 or more. A relatively high proportion of the inner city doctors were women, 24% compared with 12% in other areas, and the proportion who trained in Asia was 24% in the inner city areas 15% elsewhere – but this last difference did not quite reach statistical significance.

Looking at *country of qualification*, 75% of the general practitioners qualified in Great Britain, 5% in Ireland, 17% in Asia and 3% elsewhere. The numbers are only large enough to make comparisons between those qualifying in Great Britain and Asia. Comparatively few of those who qualified in Asia were under 40 (10% compared with 35% of those qualifying in GB), members of the Royal College of General Practitioners (5% against 25%) or trainers (2% against 12%) but there were no significant differences between the two groups in relation to sex, size of list, nor in their views on whether they were able to give enough time to people who were dying. But people whose doctors qualified in Asia had fewer home visits (an average of 4.4 in the year before they died compared with 7.7 for those whose doctor qualified in GB); they had fewer consultations altogether (8.0 compared with 10.6) but more consultations at the surgery (3.5 against 2.8). In addition, more of those qualifying in Asia were regarded as reluctant to visit: 24% against 11% of those qualifying in Britain.

Another difference was that more of the doctors who qualified in Asia were described as not easy to talk to (19% compared with 10%). Also, their care of the person who died was more often felt to be 'not very understanding' (16% against 6%) and as 'poor' (16% against 6%). It is possible that some of the adverse assessments might result from racial prejudice, but the difference in the number of home visits in conjunction with the assessments about being reluctant to visit, suggest that people with doctors who qualified in Asia may be receiving less care from their general practitioners as well as having more communication problems than people whose doctor trained in Britain.

Discussion

Although most of the people interviewed praised, or were satisfied with, the care given by general practitioners to the people who died, both the statistics and the quotations reveal some disconcerting inadequacies in this care. One problem is the unwillingness of some people to recognise or admit to their sickness and to seek help for it. Another is the difficulty some general practitioners have in coping with their own emotional reactions to death and dying, and, related to this, their inability to give appropriate care and support to people who are dying and their relatives. Only a quarter of the doctors had had any specific training in the care of the dying or management of bereavement and this study did not show any obvious benefits of this training to either the doctors themselves or their patients. Nevertheless half or more of the doctors thought it would be helpful to have further training in various aspects of this type of care.

A further problem for the general practitioners is lack of time and this was a particular difficulty for those with large numbers of patients on their lists. This was clear from the reports of the doctors and also from the smaller numbers of visits made to the people in our sample by doctors with larger lists.

Home visiting was much appreciated when it happened, but the lack of it, or its rarity, was the most frequent criticism made of the care given by general practitioners to people in the year before they died. A study of elderly people discharged from hospital also identified problems with home visiting as the commonest source of complaint (Williams and Fitton 1990). The decline in home visiting by general practitioners over the last quarter of a century (Cartwright and Anderson 1981) has come at a time when it is probably more needed by the housebound and seriously ill, as hospital stays have shortened and there is more and more emphasis on community care. The many comments and illustrations about the need for more home visiting do not suggest that visits by other members of the primary care team would be a satisfactory alternative to the doctor as it was usually medical observation and diagnosis that seemed to be needed. In one instance support was given almost entirely by the receptionist over the telephone, support which was much appreciated by the patient at the time but which appeared quite inappropriate and inadequate in the long run. Selective home visiting might also overcome some of the reluctance of some elderly people to reveal the nature and extent of their ill health.

Gray in his 1977 James Mackenzie lecture (1978) emphasised the importance of home visiting by general practitioners. He was aware that this view was unpopular and contrary to trends in this country and across the Western World. He thought history might show him as a latter day Canute proverbially struggling to stem the tide. This study has shown some of the ill effects of that tide, but has also demonstrated the appreciation and gratitude of patients and relatives to those general practitioners who still stand out against that trend and give support and care in people's homes during the last year of their lives.

A possible way to help stem this tide is also demonstrated by this study: one way to audit care in general practice is by taking a sample of deaths and retrospectively looking at the care given in the months beforehand. If such studies were done at a local level they would reveal the good care as well as any gaps and inadequacies. And results from this study suggest that home visiting would be an important part of good care for this group of patients.

References

Bowling A and Cartwright A (1982). Life after a death: a study of the elderly widowed. London and New York, Tavistock.
Cartwright A and Anderson R (1981). General practice revisited. London and New York, Tavistock.
Cartwright A, Hockey L and Anderson JL (1973). Life before death. London and Boston, Routledge and Kegan Paul.
Cartwright A and Smith C (1988). Elderly people, their medicines and their doctors. London and New York, Routledge.
Cartwright A and Seale C (1990). The natural history of a survey: an account of the methodological issues encountered in a study of life before death. London, King's Fund.
Cartwright A (In draft). Changes in life and care in the year before death – 1969–1987.
Gray DJP (1978). Feeling at home. Journal of the Royal College of General Practitioners, 28: 6–17.
Haines A and Booroff A (1986). Terminal care at home: perspective from general practice. British Medical Journal, 292: 1051–3.
Office of Population Censuses and Surveys (1989) Mortality statistics 1986. London, HMSO.
Royal College of General Practitioners, Office of Population Censuses and Surveys and Department of Health and Social Security (1990) Morbidity statistics from general practice, third national study, socio-economic analyses. 1981–82. Series MB5 No. 2. London HMSO.
Seale C (In draft a). Death from cancer and death from other causes: the relevance of the hospice approach.
Seale C (In press). Caring for people who die: the experience of family and friends. To be published by Ageing and Society.
Williams EI and Fitton F (1990). General practitioner response to elderly patients discharged from hospital. British Medical Journal, 300: 159–161.

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Although many people now die in hospital the majority spend most of the last year of their lives under the care of their general practitioner. The way general practitioners cared for a random sample of adults who died in 1987 is described in this booklet.

Assessments of the quality of this care were made by relatives and others close to the people who died and are related to characteristics of the doctors and their practices. Poignant quotations illuminate the statistics and highlight both good and bad aspects of care. The views and experiences of the general practitioners who cared for the people who died reveal some of their problems and uncertainties, and give this picture of life and care in the year before death an additional dimension.

General practitioners will be fascinated to read about the qualities and shortcomings of their colleagues. There are lessons to be learned by all those concerned with the organisation of general practice and there is a suggestion about a useful way to audit general practitioner care.

The data come from a survey which was described in a book published by the King's Fund recently: *The natural history of a survey: an account of the methodological issues encountered in a study of life before death* by Ann Cartwright and Clive Seale.

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