

Home or hospital? Terminal care as seen by surviving spouses

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SUMMARY. Among 276 married patients with cancer under the age of 65 who died in two South London boroughs during the period 1967 to 1971, 41 were still under active treatment at the time of death. I studied the remaining 85 per cent who experienced some form of terminal care, and in particular compared reports by the surviving spouses of 65 patients whose care was home-centred and 100 hospital-centred patients.

Although home-centred care was most often chosen for patients who were said to have had little severe pain before the period of terminal care, during that period there was a sharp increase in reports of pain, much of it severe and unrelieved. Hospital-centred patients were said to have had much less pain and more confusion during the final phase of care and were more likely to have been confined to bed than those at home. The amount of anxiety reported by the patient's spouse was not markedly different under the two patterns of care, nor did the pattern of care influence subsequent adjustment to bereavement.

Qualitative differences between the two groups are considered and it is concluded that although home-centred care can be successful it is often associated with unnecessary suffering. Implications for the home care of the terminally ill are discussed.

Introduction

ALTHOUGH only a minority of British people die at home a large proportion spend some part of their last year of life at home and about half receive some form of nursing care at home (Cartwright *et al.*, 1973). In particular, Ward (1974) has shown that in the care of terminal cancer patients in Sheffield "the greater share of the burden of care fell on the home".

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Cartwright interviewed a large stratified sample of surviving relatives of patients from all over Britain. Among those patients who had been admitted to hospital but had subsequently been discharged and died at home no less than 84 per cent were said to have suffered "very distressing symptoms". Pain, sleeplessness, vomiting, anorexia, constipation, bed sores, dyspnoea, and depression all increased in incidence after discharge from hospital and there is evidence of a considerable amount of suffering.

Cartwright's figures give no grounds for satisfaction and we clearly need to know more about the various patterns of care which are provided during the terminal period and the problems for both patient and family which are associated with each pattern of care if we are to improve standards of care.

My findings are reported of a study of the views of surviving spouses concerning the care given to cancer patients whose condition deteriorated and ended fatally after active treatment (seeking to prolong life) had been completed.

Method

With the assistance of the Registrar General's Office we were able to write to spouses under the age of 65 of unselected persons who had died of cancer in the south London boroughs of Lewisham and Bromley during the period 1967 to 1971.

Older respondents were not included for fear that their memory of the events leading up to the patient's death would be impaired.

Those who could be located and who agreed to help were subsequently visited in their homes on average 13 months after bereavement (\pm two months). The interviewers were mature women selected for their tact and sensitivity. Interviews were open-ended and semi-structured: the interviewer had a series of questions to which she sought an answer, but she encouraged the respondents to talk freely about the topics raised and recorded relevant verbatim comments to illustrate and expand the information obtained.

Questions focused mainly on the period of care from

Table 1. Source of sample.

Number written to	435
Moved away or not located	64
Dead, too ill, or unable to communicate	12
Preferred not to participate	107 (25)
Interviewed for study	276

the end of active treatment to the patient's death. This was termed the "period of terminal care". It was further subdivided into phases according to the site of care (at home or in hospital). Separate information was obtained about the patient's pain, mental state, and insight, and the respondent's own anxieties and reactions to each successive phase of terminal care. Particular attention was paid to the amount and duration of any pain said to have been experienced by the patient because this was the most prominent cause of distress and, when unrelieved, could usually be regarded as an index of inadequate terminal care.

We did not press respondents to answer particular questions if they found them distressing. Usually, however, the interviewers formed a good relationship with the respondents and were able to help them through any episodes of distress which were evoked by the interview. Consequently most respondents seemed glad of the opportunity to talk about this period of their lives.

Analysis of the quantitative data was conducted by parametric and non-parametric means, as appropriate. When percentages are reported "not knowns" are not included in the data base.

Results

Out of 435 surviving spouses contacted, 276 took part in the study (Table 1). Respondents comprised 147 widows and 129 widowers of mean age 57 years. They came from all social class groups (Office of Population Censuses and Studies, 1970): social class 1, 12 per cent; 2, 18 per cent; 3, 46 per cent; 4, 17 per cent; and 5, six

per cent. Nearly half were in social class 3 (skilled manual).

To test the reliability of the interviewers' assessments of pain, 15 interviews were attended by a psychologist who made her own ratings of severity and continuity of pain independently of the interviewer. There was complete agreement regarding maximum severity of pain on a six-point scale in 11 cases with one-point disagreement in two and the remaining two cases rated as "not known" by the psychologist. Continuity of pain was rated on a five-point scale. Here there was complete agreement in ten cases, one-point disagreement in two, and three were rated as "not known" by the psychologist.

Patterns of care

Forty-nine patients (18 per cent) were still under active treatment at the time of their death, but for the great majority (82 per cent) there was a period of time between the end of active treatment (aimed primarily at prolonging life) and the patient's death. This is the period of terminal care.

The duration of terminal care varied greatly with a median of nine weeks. One third (74) died within four weeks of the onset of terminal care, another third (77) died within five to 15 weeks, and only two survived for more than two years. One hundred and thirty-eight patients (62 per cent of those who received terminal care and half of the total sample) spent some of the terminal period at home. One hundred and sixty-two patients (73 per cent of those who received terminal care and 60 per cent of the total sample) spent some of the terminal period in hospital, and all of these died in hospital. In all, patients in the sample spent 3,467 weeks at home (median 20 weeks per patient) and 1,067 weeks in hospital (median four weeks per patient); that is, they spent three and a half times as long at home as in hospital.

The total sample is shown in Table 2.

For the purposes of further analysis subdivisions 1 and 8 were omitted and subdivisions 2, 3, and 4 were combined to form the "home-centred group". Groups

Table 2. Analysis of total sample.

		Number	Percentage
Home-centred	1. No terminal period (died under active treatment)	49	18
	2. Died at home after spending 5 or more weeks there	31	11
	3. Died after shorter periods at home	18	7
	4. At home 5 or more weeks; admitted to hospital to die within 1 week	18	7
Hospital-centred	5. Part of terminal period at home. Died after 1-6 weeks in hospital	47	17
	6. No terminal period at home. Died after 1-6 weeks in hospital	46	17
	7. Died after 6 or more weeks in hospital	49	18
	8. All other cases; most had readmissions to hospital or the respondent was unable to give reliable information	18	7
Total		276	100

Table 3. Comparison of home-centred and hospital-centred care—features present before terminal period (figures in percentages).

		Home-centred n = 65	Hospital-centred n = 100	Probability
Sex of patient	Male	68	66	N/S
	Female	32	34	
Mean age of respondent		61	55	N/S
Socio-economic status	GRO Group I-II	35	31	N/S
	III	42	49	
	IV-V	24	21	
Intelligence of respondent (interviewer's estimate)	Bright – very bright	27	22	N/S
	Average	62	68	
	Below average	12	10	
Anxiety of respondent	Great or very great	60	61	N/S
	Other	40	39	
Marriage (interviewer's impression)	Happy	63	68	N/S
	Unhappy or mixed	22	20	
	Insufficient information to make assessment	15	12	
Pain of patient	Severe and mostly continuous	6	19	< 0.05
	Other	94	81	

N/S = not significant.

5, 6, and 7 were similarly amalgamated to form the "hospital-centred group".

Hospital care for the terminally ill in the area of study is provided by a number of general hospitals and St Christopher's Hospice, Sydenham. Because the care provided at St Christopher's is different from that provided in most other hospitals, and definitely atypical of the country as a whole, 44 patients who had died there were made the object of a separate study and were excluded from further analysis here. We are left with 165 respondents, 65 of whose spouses received home-centred care and the remaining 100, hospital-centred care.

Comparison of home-centred and hospital-centred care

In comparing the two main patterns of care it is important to recognize that each was given for a reason—there was nothing fortuitous in the assignment of patients to either pattern of care. However, it was not always obvious to the interviewer why one patient had remained at home throughout most of the terminal period whereas another had spent the entire time in hospital.

A comparison of the features of the home-centred and hospital-centred groups which were present before the terminal period, and which might have been expected to determine which form of care would be selected, is shown in Table 3. It is clear that the two groups are of similar age, sex, and socio-economic

status and that such factors as the intelligence level of the patient's spouse, the extent to which he or she recalls being greatly anxious, or whether the marriage was seen as happy or unhappy do not seem to have had much influence on the decision as to whether the patient should be cared for at home or in hospital.

Only one factor emerges as a significant determinant of the pattern of care. Six per cent of the home-centred and 19 per cent of the hospital-centred patients were said to have suffered severe unrelieved pain before the terminal period ($p < 0.05$; X^2 test).

Other factors which may have played a part but which were not examined systematically include the type of tumour and the patient's attitude to hospitals and to the family members, general practitioners, and district nurses who were expected to care for him or her at home. To judge from the interviewers' reports these may well have been important determinants.

The penultimate phase of care

Forty-three patients had been cared for at home during some part of the terminal period but had subsequently been admitted to hospital and died there (subcategories 4 and 5). During the period at home they remained mobile (only seven per cent were confined to bed) and were unlikely to have been very confused (five per cent), but 40 per cent were said to have suffered severe pain and often this gave rise to their admission to hospital. The proportion of spouses reporting great or very great anxiety during this period (61 per cent) was no greater

Table 4. Comparison of home-centred and hospital-centred care—features of patient during final phase.

		Home-centred n = 65*	Hospital-centred n = 100*	Probability
Mobility	Full bed	6 (9.5)	45 (51)	< 0.001
	Intermediate	45 (71)	43 (49)	
	Fully up	12 (19)	0 (0)	
Pain	None to mild	19 (31)	34 (40)	< 0.01
	Moderate	13 (21)	32 (37)	
	Severe to very severe	29 (48)	19 (22)	
Confusion	None to mild	40 (68)	26 (29)	< 0.001
	Some to mixed	10 (17)	44 (49)	
	Very confused or unconscious	9 (15)	19 (21)	
Insight	Fully aware of prognosis	9 (14)	11 (11)	N/S
	Partially aware	14 (22)	25 (25)	
	Respondent doubtful	24 (37)	39 (39)	
	Unaware of prognosis	18 (28)	24 (24)	

*Percentages allow for a few "not knows".

than the proportion before the terminal period (Table 3).

The final phase

Table 4 shows the comparison between the assessments of the patient's state during the final phase of terminal care at home or in hospital. Because very brief terminal admissions hardly give the hospital a chance to obtain symptom control, patients who spent most of their time at home and entered hospital to die in less than a week

(subcategory 4) have been assigned to the home-centred group, and figures refer to their last period of care at home. Apart from this the figures in the table refer to the period preceding the patient's death.

It is clear from the table that people dying at home were much more likely to remain mobile and in clear consciousness than patients dying in hospital, but they were also likely to suffer more pain. In fact nearly a half were said to have suffered severe or very severe pain at home. The extent to which this pain was relieved can be seen in Figure 1. This enables us to compare the proportions of patients with pain before the terminal period and during the final phase of care at home or in hospital.

Among home-centred patients, six per cent were said to have suffered severe and mostly unrelieved pain before the period of terminal care, and this percentage rose to 28 per cent during the final phase of care at home ($p < 0.002$; X^2 test).

Among hospital-centred patients 20 per cent were said to have suffered severe and mostly unrelieved pain before the period of terminal care, and this proportion did not change during the final phase of care in hospital (comparable figures for patients dying at St Christopher's Hospice were 36 per cent and eight per cent. The implications of this finding will be considered in a later paper).

In neither home nor hospital were patients likely to have been thought by their surviving spouse to have been fully aware of the prognosis before death. On the other hand, only about a quarter in each setting were said to have been totally unaware of the prognosis. More often the patient had given some indication that

Figure 1. Proportions of patients with severe and mostly continuous pain.

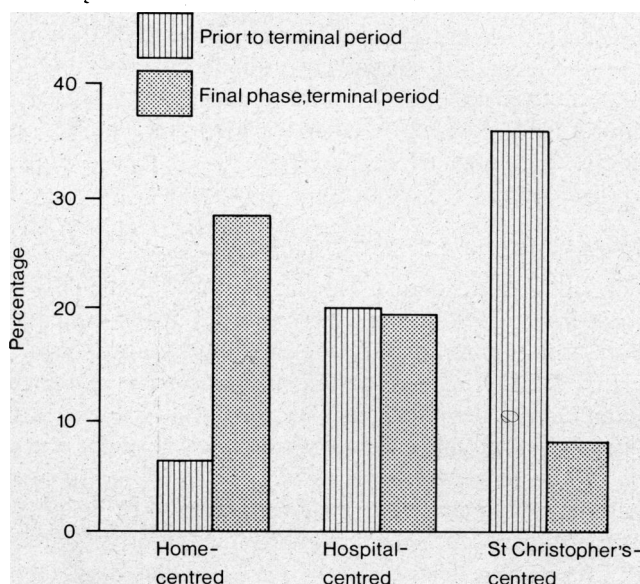


Table 5. Comparison of home-centred and hospital-centred care—reactions of patient's spouse during the final phase.

	Home-centred n = 68	Hospital-centred n = 100	Probability
<i>Respondent felt "great" or "very great" worry about:</i>			
Physical pain and its relief	25 (44)	26 (30)	N/S
Revealing fears to spouse	24 (41)	43 (51)	N/S
Own future	7 (12)	27 (31)	< 0.02
Being unable to go on	11 (20)	14 (16)	N/S
Separation from spouse if he/she had to be moved elsewhere	6 (11)	5 (6)	N/S
Others handling or harming patient	4 (7.6)	11 (13)	N/S
Future of children or other dependents	2 (3.6)	9 (10)	*
Mean "worry" score	9.3	9.7	N/S
Self-rating anxiety as "great" or "very great"	47 (82)	78 (87)	N/S
<i>Psycho-physical "stress" symptoms</i>			
Mean score	0.88	1.18	
<i>Emotional control:</i>			
Respondent failed to hide feelings of fear	8 (14)	17 (20)	N/S
Respondent failed to express positive feelings	4 (7.4)	4 (4.8)	N/S
<i>Role performance</i>			
Respondent unable to provide necessary care for dependents (moderate—very great)	0 (0)	9 (10)	*
Respondent unable to perform normal work tasks (moderate—very great)	4 (7.2)	6 (7.1)	N/S

*Chi-squared test not applicable.

he knew the prognosis might not be good but had avoided, or been prevented from, frank discussion with his spouse. These figures should not, therefore, be taken as evidence of the patient's degree of insight but rather of the lack of communication between husband and wife regarding the whole question of survival. As one put it, "He used to say, 'I'm not going to die, am I?', and I'd reply, 'No, you're strong, you're the last man in the world to die'."

Because the diagnosis of 'cancer' is associated with a poor prognosis, we also asked how much insight the patient was thought to have had into his diagnosis. The figures were similar to those obtained for the degree of insight into the prognosis, and there were no differences between home-centred and hospital-centred care.

The stress upon the respondent in each pattern of care is shown in Table 5; it is clear that there are few differences between the groups. Spouses of patients at home were rather more inclined to worry about the relief of pain and about separation from their spouse if he or she should have to be moved elsewhere, but neither of these differences reached significance. Those at home were significantly less likely to worry about their own future and marginally less likely to worry about revealing fears to their spouse or about others

hurting or harming the patient.

Respondents whose spouses were at home were able to perform their normal work tasks as well as respondents whose spouses were in hospital, and were rather better able to care for children or other dependents.

Inability to hide fears or express positive feelings was a problem for a minority in both settings.

In general, spouses of patients cared for at home seemed to recall no more or less anxiety than spouses of patients cared for in hospital. The only general score which differentiates the two groups was the psycho-physical stress symptom score. This was obtained by adding together six five-point scales concerning the commoner psycho-physical accompaniments of anxiety (anorexia, weight loss, insomnia, tremor, tiredness, and forgetfulness). The mean scores seem to indicate that spouses of hospital-centred patients suffered rather more of these symptoms than spouses of home-centred patients. However, differences are not large and, since respondents had often forgotten such details, little reliance can be placed on these figures.

Respondents' memories were fresher for symptoms which had been present since bereavement. A post-bereavement score was obtained by adding scores on 22

five-point scales about the physical and emotional accompaniments of bereavement. These ranged from measures of the intensity of pining for the lost partner to symptoms such as excessive sweating and palpitations. The mean post-bereavement score for the spouses of home-centred patients was 18.3 and for spouses of hospital-centred patients, 18.7. Clearly there is no evidence from these figures to indicate that the pattern of care provided was associated with differences in the adjustment to bereavement.

Further analysis and illustrative case histories

It would seem from the above findings that one factor which determined whether or not a patient would receive terminal care in hospital was the occurrence of severe unrelieved pain during the earlier period of care. There is no reason to believe that hospital-centred patients suffered any less pain during the terminal period, but at least their pain did not get any worse. On the other hand the incidence of severe pain increased in patients who remained at home throughout most of the terminal period and half of these suffered severely or very severely, much of their pain being unrelieved and continuous. These patients usually remained out of bed and in clear consciousness throughout the period of terminal care.

When men and women were analysed separately the only difference was that widows reported rather more anxiety and distress during and after the terminal phase than widowers. (The mean worry score during the final phase of the terminal period was reported to be 9.0 by widows and 7.0 by widowers. The mean post-bereavement score for widows was 24.0, and for widowers, 14.4).

To learn more about the reasons for the differences between home-centred and hospital-centred groups a close study was made of the detailed interview reports concerning 35 home-centred and 26 hospital-centred patients. From these it seems that home can be the best place or the worst place to die. Given a confident and co-operative patient, whose family collaborate well with a willing general practitioner skilled in the proper use of drugs, a district nurse who is backed by adequate local services, and provided the illness does not go on so long that it exhausts the resources of the family, there is no reason why terminal care cannot be provided at home.

Unfortunately only ten of the 35 examples of home-centred care which we studied fulfilled all these criteria. Of the remainder, there were ten patients who seem to have been inadequately supported by the medical/nursing team, five whose closest relatives were unable to give adequate support, at least two patients who would not co-operate by accepting hospital admissions when it was needed, and in six others inadequacies seem to have interacted so that blame becomes hard to assign. These inadequacies seem to have resulted in failure to relieve pain in 15 patients (43 per cent), failure to relieve other distressing symptoms in four (two of whom also had unrelieved pain), isolation and loneliness in three, and

mental illness necessitating hospital admission of the spouse in one.

The most frequent unsatisfactory pattern was inadequate pain relief. This seems most often to have been due to failure on the part of the patient's general practitioner to ensure that regular doses of the appropriate analgesics were given in sufficient dosage to prevent the pain from becoming severe, or to arrange hospital admission if this failed. However, other factors reflected misunderstandings on the part of the patient or family members. Thus, it seems several patients put up with unnecessary pain without complaint on the supposition that nothing could be done to relieve it or that their chances of recovery would be improved if they abstained from the use of powerful analgesics.

A man of 54 was nursed at home for five months before his death. During much of this time, his wife asserts, he was in severe pain and "he cried like a baby all the time." He was so frightened that he clung to his wife and would become "hysterical" whenever she left the room. His general practitioner came in once a week to give him an injection but told his wife that no hospital bed was available. Eventually a bed was found and he was admitted to hospital where he was heavily sedated and died three days later. When interviewed a year after this his wife was still emotionally disturbed and preoccupied with nightmarish recollections of this period of her husband's life.

We might have been inclined to put this story down to neurotic exaggeration if it had not been repeated by others so many times in the course of the study. Many patients became increasingly fearful as their illness progressed and their fear itself may have increased their susceptibility to pain; but it also caused some patients to refuse treatment or hospital admission.

A man of 50 returned home from hospital after removal of his bladder for a 'cancerous growth'. Although he had been told his diagnosis he assumed that the operation had been a success and that the danger was past. Very soon, however, he developed severe intermittent pain and faecal incontinence. This distressed him greatly and he became agitated if left alone. Within a few weeks the pain had become very severe. His general practitioner was sympathetic but failed to relieve the pain and is said to have told the patient's wife that her husband would have to be told the truth about his illness if he was to be admitted to hospital. Such was the patient's fear of dying that his wife preferred to keep him at home rather than risk aggravating his distress further. The consequences of this decision seem to have been disastrous and, in the course of the last few weeks of her husband's life, the wife claims she got very little sleep and lost 3½ stone in weight. The patient's pain was continuous and often extreme and he was in great distress up to his death. Subsequently his wife remained emotionally disturbed and remorseful. She endeavoured to escape from the memories of her husband's illness and death by selling the home and moving out, but to no avail. When seen by our interviewer she was still intermittently agitated and her post-bereavement score was high.

Stoicism, verging on needless heroism, was a complicating factor in several compulsively self-reliant men. Reluctance to complain sometimes led to a late diagnosis being made and inadequate relief of symptoms.

One man, for instance, would never admit to his wife or his general practitioner that he felt ill. Only after he became delirious did the general practitioner insist on a chest x-ray, which revealed lung cancer. When the diagnosis was explained to him the patient refused surgery and radiotherapy. He discharged himself and returned to work until two days before his death. During this period his heroic stance was admired by all: "Sometimes I saw him coming down the road looking dreadful," says his wife, "but he'd straighten up as soon as he saw me . . . He must have suffered a lot of pain."

In other cases family members seem to have regarded any suggestion that hospital admission might be needed as a reflection on their own willingness or ability to provide proper care.

One man refused to allow his wife to have any radiotherapy or other treatments and would not sign the forms which would have enabled home help and night nursing support to be provided for her at home. "No help, no nothing!" he exclaimed. When, predictably, his efforts to nurse her himself proved inadequate to relieve her increasing pain he became extremely agitated. He persistently refused offers of hospital admission, however, until after she had sustained a pathological fracture of her arm.

By contrast, the story of a married man, aged 65, can be regarded as an example of successful home care.

Closely supported by a general practitioner who knew him well, the patient returned home from hospital after investigation had shown him to have an inoperable abdominal tumour. He remained at home for the remaining five weeks of his life in the care of his wife. The patient was a calm, placid man and his general practitioner decided that he should be told the truth about his condition. He took the news in exemplary fashion and peacefully prepared himself to die. His wife felt that this attitude to his illness made it possible for her to remain open and frank with him and relieved much of the strain on her.

Unfortunately it soon became obvious that drugs by mouth were not adequate to relieve his pain and that four-hourly injections would be needed. The patient's wife was horrified when the general practitioner suggested that she learn to give the injections, but "I couldn't expect the doctor to keep calling", and since she was determined to keep her husband at home she steeled herself to learn the necessary technique. His death, when it came a week later, was peaceful. Although she admits that the last few days were a considerable strain and she lost weight and slept badly during the first few months of her bereavement, she then picked up and when seen at interview had regained her lost weight and was making a good adjustment to life as a widow.

Among the various subdivisions of home-centred care category 4 (at home five or more weeks, admitted to hospital to die within a week) was the least satisfactory. Too often the patient had been kept at home too long and sent into hospital too late. Consequently, the family were exhausted and care had often gone hopelessly wrong, admission being seen as a sign of failure. By the time the patient entered hospital he or she was very weak and the emotional trauma of admission in these circumstances may well have shortened life.

Hospital care seems to be indicated whenever it is clear that, for whatever reason, adequate terminal care cannot be provided at home. Sometimes a brief stay in

hospital, to give the family a rest or enable medication to be reassessed and adjusted and pain brought under control, will enable the patient to return home again and there is no need to regard the hospital as a 'last resort'. Such brief admissions have the added advantage that they get the patient used to the hospital and help to allay unrealistic fears.

Focusing on the 26 hospital-centred cases which were more closely studied, over half the patients (14) were said to have had symptoms which were so severe that it was not thought possible to control them at home and a quarter (seven) were thought to have been in hospital to relieve or avoid strain on the spouse. In the remaining five we were unable to ascertain why the patient was kept in hospital.

Hospital care seems to be likely to succeed when:

1. Adequate relief of physically distressing symptoms can be obtained.
2. Attention is paid to the needs of the patient for emotional support and understanding.
3. Similar support is given to the family.

Our data do not enable a very satisfactory assessment of these criteria, but there were 12 cases (46 per cent) where critical comments threw doubt on the adequacy of care. In five cases there seems to have been little communication between the doctors and the spouses. Two complained that they did not see a doctor during the whole of the patient's terminal stay in hospital, and a third said that the only time she had seen a doctor was when one came to ask her for her husband's kidneys. Another wife claimed that she had never been told that her husband had cancer and disbelieved the interviewer when she quoted the death certificate. Others complained that ward staff were always "too busy" to see them and that they ignored the stress which the family were under.

Pain would appear to have been less of a problem in hospital than it was at home but, as we have seen, 20 per cent of hospital-centred patients were said to have suffered severe and mostly continuous pain and comparable figures from St Christopher's Hospice suggest that this is a higher proportion than necessary. Several patients had been greatly distressed by unrelieved dyspnoea.

Other criticisms were levelled at the general standard of care. Respondents objected to the needless prolongation of a miserable life by tube feeding, and the tendency for ward staff to focus their attention on patients who were improving and to ignore dying patients (as evidenced, in one case, by unemptied urine bottles and in another by the slow response of the nurses to requests for help). We did not investigate any of these claims and they were not frequent enough to allow general conclusions to be drawn. All that we can say is that although most respondents were satisfied with the care which their spouse had received in hospital, there were many who were not.

Discussion

Although our data are drawn from a particular part of London there is no reason why the results of this study would have been different if it were carried out in other parts of Britain. On most points at which comparison can be made our figures do not differ greatly from the Registrar General's national figures or from Cartwright's stratified national sample. Within the age range studied the age and sex distribution of our sample resembles national norms. As in other studies, about one third of our sample died at home and pain was the most frequent and distressing symptom.

The losses to the sample by refusal and moving away are typical of studies of bereaved people. In the Harvard Bereavement Study, in which refusers were followed up by telephone a year after bereavement, there was no evidence that their long-term adjustment was any different from that of non-refusers (Parkes and Brown, 1972).

The main bias of our sample, however, derives from the exclusion of patients over the age of 65 and of patients without a surviving spouse. Both of these criteria exclude patients who are likely to pose special problems for home care services and we should take this into account in drawing conclusions from the current study.

The comparison of home and hospital-centred care is complicated by the fact that it was the patients who had less pain before the terminal period who were most likely to be sent home and to remain at home. This fact serves only to accentuate the most important finding to emerge from this study—that terminal care at home was associated with more pain and more problems in the relief of pain than hospital care. In general it appears that, as the illness progressed, many of these cancer patients tended to experience increasing pain. Among patients who were admitted to hospital or who remained in hospital throughout the period of terminal care this increase in pain was checked, but at the cost of loss of mobility and a greater tendency to become confused (presumably as a consequence of the narcotic drugs which were administered). Patients who remained at home, however, ran the risk that they would suffer severe pain, and in nearly a third this was said to have been mostly continuous.

From the point of view of the patient's spouse there is some inconclusive evidence that home care was associated with rather less psychosomatic stress than hospital care, despite the anxiety associated with inadequate relief of pain, but in the long run spouses who had nursed a patient at home for a long time did not find themselves less disturbed after bereavement than those whose spouses had received hospital-centred care.

Despite these figures it would be misleading to conclude that hospital-centred care is preferable to home-centred care. We came across many instances in which home care had been extremely successful and

others in which hospital care had clearly failed to relieve distress in either patient or relative. Reasons for the occasional failure of hospital care have been touched upon and further discussion of these will be carried out in a later paper. The important issue for this paper is to examine the possible remedies for the frequent failure of home care. Although our evidence is by no means conclusive it seems that general practitioners often failed to prescribe drugs which are usually needed for the relief of chronic pain in the later stages of cancer and to provide the close supervision which is needed if optimal pain relief is to be obtained.

As Twycross (1975) has pointed out, since most analgesics provide pain relief for only three to six hours, it is necessary to administer such drugs at frequent intervals if we are to prevent continuous pain from becoming severe. There is no 'correct' dosage level; the amount of drug needs to be 'titrated' against the pain until the smallest dose which prevents pain has been discovered. Given in this way it is usually possible to maintain the patient in a pain-free state on oral medication and without undue blurring of consciousness throughout the terminal illness. As time passes it may be necessary to increase the dosage of drugs to maintain the pain-free state and to progress from synthetic analgesics to the more potent narcotic drugs (morphine or diamorphine), but the dosage of these can be kept to a minimum by combining them with a tranquillizer (such as prochlorperazine or chlorpromazine). In exceptional cases it is necessary to administer the drug by four-hourly injection (when the equi-analgesic dose of morphine or diamorphine will be found to be a half the dose given by mouth).

This is the pattern of drug administration employed by Cicely Saunders and her colleagues at St Christopher's Hospice and it is well suited to use in home-centred care, provided the general practitioner is willing to give the time and attention which is necessary if the proper dosage level is to be established and maintained.

Since the data for this study were collected the views of the hospice staff on pain control have been widely disseminated and it may be that some improvement has taken place in the standard of care. It is hoped to replicate the study over the next few years to ascertain if this is the case.

Prevention of pain may be the first requirement for successful home care but it is not, of course, the only one. The progression of a terminal cancer is a source of great stress to patient and family alike. Any family member without professional nursing experience who accepts responsibility for the day-to-day care of a very sick person at home is going to need support from the primary health care team. Given encouragement and adequate information about the illness and about the resources available (which should include an assurance that rapid help is available on demand at any time of the day or night), family members will usually find that they can cope very well with the demands of the situation. An inpatient unit which is willing to take over

OCCASIONAL PAPERS

The *Journal of the Royal College of General Practitioners* has introduced a new series of publications called *Occasional Papers*. The prices shown include postage and copies can be obtained while stocks last from 14 Princes Gate, Hyde Park, London SW7 1PU.

OCCASIONAL PAPER 1

An International Classification of Health Problems in Primary Care

The World Organization of National Colleges and Academies of General Practice (WONCA) has now agreed on a new, internationally recognized classification of health problems in primary care. This classification has now been published as the first *Occasional Paper*. Price £2.25.

OCCASIONAL PAPER 2

An Opportunity to Learn

Occasional Paper Number 2 is the report of Dr E. V. Kuenssberg, the Wolfson Visiting Professor, which describes his visits to many countries of the world, his assessments of general practice, its organization, development and future. Price £2.25.

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Trends in National Morbidity

The third *Occasional Paper* from the Birmingham Research Unit compares and contrasts the changes found on analysing the results of the two national morbidity surveys in Britain. Price £2.25.

OCCASIONAL PAPER 4

A System of Training for General Practice

The fourth *Occasional Paper* by Dr D. J. Pereira Gray is designed for trainers and trainees and describes the educational theory being used for vocational training in the Department of General Practice at the University of Exeter. Price £2.75.

whenever family or patient become over-anxious or symptoms emerge which cannot be adequately relieved at home and which can provide outpatient support before admission, is essential and, if introduced at an early stage as an additional source of support rather than a last resort, can be a valuable extension of the home-care programme.

This study has confirmed the observations of Kübler-Ross (1970), Hinton (1967), and Glaser and Strauss (1968) that although most dying patients do not communicate openly with others about the nature of their illness and prognosis, it is unusual for them to express outright denial of the true facts. Doctors have been criticized in the past for concealing facts about a terminal illness from their patients, but this criticism was rarely made by the respondents who took part in the current study and they do not appear to have taken advantage of their position as principal caregivers during periods of care at home to encourage communication about the diagnosis and prognosis.

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Prescription-writing by receptionists

Of all the letters concerning prescription-writing by doctors' receptionists I have the best one ever today: one item having six mistakes. The prescription was written by the receptionist for 'Steladex' tablets, with no quantity or directions; it was unsigned and dated for the middle of March.

To cap it all, the patient had been informed by the receptionist that the prescription was correct, as she had experienced difficulties on previous occasions.

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