

The care of patients dying from cancer

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SUMMARY. A census of seriously ill cancer patients at home and in hospital was undertaken in 1977 in Southampton Health District. One hundred and thirty-seven patients were identified in whom no further curative treatment was appropriate. Ninety-seven (71 per cent) were interviewed, 63 at home and 34 in hospital. Thirty-four per cent of patients reported moderate or severe pain in the 24 hours prior to interview. Similar proportions were found in the home and in hospital. Only 5 per cent were receiving oral diamorphine. Night nursing and home help services did not meet the needs of the patients.

Introduction

VARIOUS surveys of the dying (Cameron, 1950; Exton-Smith, 1961; Cartwright *et al.*, 1973) have been undertaken, retrospectively examining medical records after death or interviewing relatives. Other surveys have concentrated on patients in hospital (Exton-Smith, 1961; Hinton, 1963; Saunders, 1978; Twycross, 1975) or in the community (Wilkes, 1964 and 1969). The present study was cross-sectional, based on a census of seriously ill cancer patients at home and in hospital. Patients and their relatives were approached directly.

Method

The census was undertaken in Southampton Health District in early 1977 in order to provide a cross-sectional measure of prevalence of all forms of malignancy. Ward nursing staff were asked to identify patients in consultation with a hospital doctor and to report cases present on the ward at 12.00 on a particular day. Cases were defined as any patient over the age of 15 years with advanced cancer, or who was likely to die from cancer within a period of about six weeks. Six weeks was chosen because of the need to visit a group of these patients subsequently.

A separate request was also made to all general practitioners for information about any cases (as de-

finied above) whom they had visited at home in the previous 30 days. A similar list was requested from attached community nurses. Although every case appearing on the nurses' list was identified by the doctors, a far larger group of patients was identified at home by the latter; furthermore, many of them were in an earlier stage of their disease.

The survey was conducted by one doctor (the author) and two nursing sisters, both of whom had had experience of patients in this field. An interview form was completed with the patient and a responsible relative. In hospital the patient and the ward sister completed this part. There were ample crosschecks of information so that validation was possible. Relatives were also asked to fill in a questionnaire later.

Three main measures of need were assessed: dependency, symptom control and awareness.

The relatives' questionnaire was completed at the time of the patient interview if the relative was available, or by post if necessary. This questionnaire sought information about the strain that relatives experienced and the practical help they might have appreciated which the NHS was unable to provide.

Results

From a total of 157 patients reported, 137 were considered suitable. Ninety-seven (71 per cent) were interviewed; 29 (21 per cent) died before interview and 11 (8 per cent) refused. The diagnoses in the census and the sample were compared with the death registrations for the Southampton Health District. The results showed that the sample was representative of the majority of patients dying from cancer, apart from an excess of breast carcinoma in women and a deficit of bronchial carcinoma in men.

Of the 97 patients interviewed, 63 were seen at home and 34 in hospital. During the ensuing three months, 34 (35 per cent) patients died, 17 in the first six weeks and 17 in the second six weeks. The sample characteristics are shown in Table 1. The mean duration of illness at the time of interview was 16.8 months at home and 11.2 months for patients in hospital, 12.5 months for men and 17.7 months for women.

Table 1. Sex and age by cancer diagnosis.

	All diagnoses	Male	Female	Age			
				15-44	45-64	65-74	75+
Buccal cavity	3	1	2	1			2
Oesophagus	1	0	1		1		
Stomach	8	7	1		5	2	1
Intestine	18	9	9		6	5	7
Larynx	0	0	0				
Lung and bronchus	23	19	4		11	9	3
Breast	21	2	19	1	7	7	6
Cervix	3	—	3	1	1		1
Uterus	1	—	1				1
Prostate	5	5	—			3	2
Leukaemia	0	0	0				
Other malignancies	20	7	13	2	8	6	4
Total	103*	50	53	5	39	32	27

*Six patients had two primary sites of cancer.

Patient activity and unmet need

Relatives played a large part in providing care and support. Only 4 per cent of patients were without any relatives at all, but 14 per cent had no one to call on in time of need. A large variety of professionals had visited the patients at home, but the most frequent visitors were the general practitioner and the community nurse. The most debilitated patients were found to be in hospital. Of patients in the community, 63 per cent were getting about at home and 5 per cent had returned to work; 10 per cent were severely handicapped or confined to bed. An area of unmet need in the community was demonstrated (Table 2), chiefly for night nursing and home help.

Symptoms

Patients were asked specifically about 20 different symptoms experienced in the 24 hours prior to interview. They were asked to rate each symptom according to a card given to them. The scale recorded 1 for no problem, 2 for a slight problem, 3 for a moderate problem, and 4 for a severe problem. Only a score of 3 or 4 was recorded as an important symptom in Table 3.

Only 10 patients out of 91 had no symptoms at all and these were mostly at home (eight). Most patients suffered four or five symptoms each, a figure similar to Cartwright and colleagues' survey (1973), which reported an average of 4.3 symptoms. Patients in hospital had an average of 5.4 symptoms, compared with 4.5 for patients at home ($t = 2.997$, $p < 0.01$). This finding confirmed the fact that the more sick patients were in hospital and that they were not admitted for purely social reasons. The commonest symptoms were weakness, loss of appetite, sleeplessness, depression, and difficulty in breathing.

Another significant finding was that 34 per cent suffered moderate or severe pain in the 24 hours prior to

Table 2. Request by relatives ($n = 68$) for more practical help at home.*

Request for	Number of patients	Percentage
Night-time help	8	12
Bathing patient	5	7
Housework	8	12
Reading to patient	4	6
Writing a letter	1	2
Cooking	3	4
Laundry	7	10
Shopping	7	10
Making a will	3	4
Someone to sit with patient	1	2
Commode	1	2
Rehousing	1	2
Total relatives requesting	18	27
None	43	63
Questions not relevant	7	10

*The question posed to relatives was, "If the patient has been staying with you, would you have appreciated more practical help than you are already receiving?"

interview. There was no difference between the relative numbers experiencing pain in the home and in hospital. For all symptoms where there were sufficient numbers for statistical testing, no difference was demonstrated between the home and hospital groups.

Staff or relatives were asked about analgesic drugs written up and those actually received by the patient (Table 4). 'Written up' in hospital meant that a drug had been ordered and written up on the patient's drug chart. In the home 'written up' was interpreted as a written instruction on the label of a bottle.

Those patients who were given strong analgesic drugs, that is diamorphine or morphine, were further investi-

Table 3. Patients with moderate or severe symptoms.

Symptom	Home	Hospital	Total number	Percentage
1. Loss of appetite	27	11	38	42
2. Nausea or vomiting	15	10	25	28
3. Flatulence	9	6	15	17
4. Weakness	29	14	43	47
5. Constipation	7	13	20	22
6. Diarrhoea	4	2	6	7
7. Unpleasant tongue or mouth	8	11	19	21
8. Difficulty in swallowing	7	4	11	12
9. Discharge of ears or eyes	1	1	2	2
10. Itching of skin	4	2	6	7
11. Frequency of micturition	6	3	9	10
12. Dysuria	1	0	1	1
13. Difficulty controlling micturition (incl. catheter)	5	6	11	12
14. Cough	11	6	17	19
15. Sputum	10	5	15	17
16. Difficulty in breathing	18	8	26	29
17. Sleeplessness	18	13	31	34
18. Depression	17	13	30	33
19. Anxiety	12	4	16	18
20. Pain	19	12	31	34
21. Other symptoms	16	1	19	19
No symptoms	8	2	10	11
Total patients	62	29	91	
Average number of symptoms (excluding those with no symptoms)	4.5	5.4		

Where numbers were large enough for statistical testing, no difference was found between the home and hospital groups except for average number of symptoms ($t=2.997$, $df=85$, $p<0.01$).

gated to find out whether the dose had been increased or reduced, given orally or by injection and the maximum dose received in a 24-hour period. There were 29 patients in moderate or severe pain, but only four received strong pain drugs (Table 5) on the day of interview. Because there can be a difference between prescribing and taking drugs, a note of both was made. Doctors may be reluctant to prescribe diamorphine, but nurses also hesitated to give it and patients were unwilling to take it regularly. Sixteen patients were written up for strong analgesics (Table 4); eight of these were taking the drug orally, and three of those were receiving diamorphine by injection as well. Only four were being given their drugs every four hours, and two were getting them twice a day or less. Dosage was also quite often small, with five patients on a total of 15 mg or less, and only six taking over 50 mg in 24 hours.

Communication

Staff and relatives were asked whether they considered that patients knew their diagnosis and were aware that they had not long to live. A separate assessment of these two questions was then made by the interviewer. It was quite clear that many more patients were aware that they were dying than ever let on to staff or relatives. Forty-one (48 per cent) patients indicated full awareness to the interviewer (Table 6), but according to the staff only 26 (30 per cent) were aware, a significant

Table 4. Patients with pain at home and in hospital.

	Home	Hospital
Patient totals	60	33
Numbers with pain	19	12
Analgesics written up		
Strong	5	11
Moderate	23	16
Mild	14	13
Analgesics actually given		
Strong	2	9
Moderate	22	8
Mild	13	4

difference ($\chi^2=4.792$, $p<0.05$). However, 10 per cent of patients expressed concern that they were not told enough about their illness.

We asked patients who knew that their prognosis was poor whether they were glad they had been informed (Table 7). Thirty-one (72 per cent) out of 43 (100 per cent) who were aware they were dying were glad to be told. Only two were actually sorry to know, but eight were undecided. There appeared to be no difference between the home and hospital groups.

Finally, the interviewer made a judgement of whether patients were aware of their prognosis. Of the 44 patients thought to be aware of this, 34 appeared to

Table 5. Patients receiving strong analgesic drugs.

Degree of pain (self-assessment)	Mild or moderate drug	Strong drug
1. Nil	38	2
2. Slight	14	3
3. Moderate	17	0
4. Severe	8	4
Patient totals	77	9

Table 6. Awareness of dying.

	Assessed by interviewer			
	Yes	No	Total	Per cent
Assessed by staff				
Yes	25	1	26	30
No	16	44	60	70
Total	41	45	86	100
Per cent	48	52	100	

Comparing interviewer with staff $\chi^2 = 4.792$, $df = 1$, $p < 0.05$.

Table 7. Patient's knowledge of prognosis.

	Home	Hospital	Total	Per cent
Yes, glad to be told	22	9	31	72
No, sorry to be told	0	2	2	5
Undecided	8	1	9	21
Qualified	0	1	1	2
Total aware	30	13	43	100
Does not know prognosis	31	14	45	
Patient totals	61 (2 missing)	27 (1 missing)	88	

accept the situation and 15 showed signs of denial. In many there were signs of such a struggle to accept or deny that they had to be classified in both.

Discussion

Symptoms

Many of the symptoms, for example weakness or loss of weight, cannot be controlled at the present time. However, a most important finding was that 34 per cent suffered moderate or severe pain, and this could have been controlled. Parkes (1975) reported a prevalence of 29 per cent in his study in two London boroughs; he also reported that very few had severe pain in St Christopher's Hospice. Severe symptoms were most commonly present amongst those with alimentary carcinomas and cancer of the bronchus. Except for

dyspnoea, symptoms were generally less evident amongst those with breast cancer.

Pain control

The success in pain control in St Christopher's Hospice (Saunders, 1978) has been attributed mainly to the use of oral diamorphine administered regularly before the pain has a chance to return. The present study showed that such methods were by no means always followed, either in amount, route of administration or frequency.

Awareness

Glaser and Strauss (1965) demonstrated the sort of contest that goes on in the ward to obtain information. For example, if a nursing sister or doctor walked past the bed without a word this might imply more to patients than a few passing remarks. Kubler-Ross (1969) has described in detail the five stages through which patients progress. I used this description as a basis for assessing patients' reactions to awareness. It was clear that patients were fluctuating between responses, even in the course of the interview. Some were passive, settling their affairs philosophically, while others were calmly resigned, nonchalant, or even, in one case, suicidal. Others seemed more active in their acceptance, living intensively or searching for a miracle cure. Denial took various forms, such as engagement in strenuous activity, as though to pretend the illness was not terminal, talking about future plans (such as buying a farm), or appearing to avoid discussing the diagnosis altogether.

After visiting the radiotherapy department one patient said, "Nurse asked me if I was having 'ray' treatment and needed an appointment. When I said 'no' she looked really scared, as though she had let the cat out of the bag." It was obvious that he knew very well what his problem was. He died three weeks later; surprisingly, his wife wrote to me and said, "He never knew he had a cancer and I was so glad I kept it from him." This illustrated the problem of, on the one hand, acceptance by the patient and, on the other, denial by the relative. An example of anger was illustrated by another patient, a young man with an osteosarcoma. He was very aggressive because he had not been told his prognosis earlier. He said, "If doctors had good news for you they were very quick to tell you—for example the bone was knitting—but as soon as my disease went wild they tended to be silent." Another man of 58 and dying genuinely believed he need not ask the doctor about his illness because he would be told if there was anything seriously wrong.

Some patients could grapple with reality more readily than others, but all needed some reason to go on living, even if it was unrealistic. However, the patients who seemed happiest were the accepting ones who did not need to deny their illness. It was much easier for staff and relatives to be relaxed and to communicate freely with them.

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Antibiotics and asthma

The value of antibiotics was assessed in a randomized double-blind study of amoxycillin and placebo in 60 adults admitted to hospital with acute exacerbations of asthma. Thirty-seven exacerbations were treated with amoxycillin and 34 were treated with placebo. Response to treatment was closely monitored but no significant difference in improvement was demonstrated between groups for length of hospital stay, time taken for 50 per cent improvement in symptoms, patients' self-assessment and respiratory function, and symptoms and respiratory function at time of discharge from hospital. Antibiotics should not be given routinely to patients admitted to hospital with acute exacerbations of asthma.

Source: Graham, V. A. *et al* (1982). Routine antibiotics in hospital management of acute asthma. *Lancet*, 1, 418-420.

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