MEDICAL PRACTICE

Contemporary Themes

Survey of distressing symptoms in dying patients and their families in hospital and the response to a symptom control team

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Abstract

The care given to 26 dying patients, and their families, being nursed in a hospital where there was no specific terminal care facility was studied. These patients were dying from both malignant and non-malignant disease. Anorexia, sleeplessness, coated or infected mouths, pain, and pressure sores were seen in half of the patients. Fear about caring for the patient at home and lack of information were the problems most frequently identified by the relatives.

As a result of this study a multidisciplinary team specialising in symptom control and supportive care has been established. On average half of the total number of patients dying from cancer in the hospital are supported by the team. The number of complaints from relatives of dying patients has been drastically reduced since the team was formed.

Introduction

Over the past 15 years hospices have emerged all over Britain, becoming places of excellence in relieving distress in the dying patient. Hospices, however, cannot cater for all the dying, and in most cases priority is given to the patient with cancer.

Recent statistics show that 60% of deaths from cancer still occur

in hospital.¹ Lunt states that patients with cancer often spend two thirds of the last months at home but need admission to hospital to die because of the lack of facilities and support at home.^{2,3} Recommendations from the nationwide survey of the quality of life before death by Cartwright *et al* emphasised the importance of the hospice skills being more widely disseminated into geriatric and short stay wards so that all dying patients could benefit.⁴ The support care team, a recent development described by Bates *et al*,⁵ was designed to promote the principles of hospice care for short stay patients and seems to be a logical response for addressing the needs of dying patients in hospital. There is little information from the hospital setting about the physical and emotional needs of these patients and families. The available information has often been derived from retrospective studies.

The purpose of this descriptive study was to look at details of symptoms and the psychosocial aspects of care for both patient and family in hospitals where there was no facility for palliative care.

Method

Patients were selected from five wards in two hospitals in the same district. Three physicians (two chest physicians and one rheumatologist who were sympathetic to the ideals of terminal care), gave consent for their terminally ill patients to be included in the study. Patients who were thought to have "less than three months to live" were referred consecutively to the study by the senior registrar on the firm.

Of the 26 patients referred, 15 were dying of cancer and 11 of non-malignant disease. Patients and relatives were approached on the seventh and 10th days respectively after admission. Patients' physical symptoms were assessed using a list of 16 symptoms, and anger, anxiety, and depression were assessed in 22 of the 26 patients interviewed. Both tools were designed from a basic four point rating scale.

A semistructured interview was designed to elicit information from relatives. In addition, each relative was asked to fill in a mood adjective check list consisting of a list of 22 adjectives describing fatigue, anxiety, depression, and anger on a four point rating scale.⁶

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Results

PATIENTS

Table I shows the range of symptoms experienced by the 26 terminally ill patients. The most common symptom was anorexia. Only two patients said that they had a good appetite; one of these was receiving steroids. Twenty one patients had badly coated tongues, 12 of whom had visible thrush (two patients were receiving antifungal agents). Mouth care every two to four hours was being performed according to the notes.

Of the 26 patients, 23 complained of a bad night's sleep. Ward noise, patients making a disturbance, and being turned in their beds too often were identified by patients as the cause. The common attitude of the patients was that they did not expect to have a good night's sleep because they were in hospital.

Twenty patients were troubled by cough or breathlessness, a reflection of the fact that these patients were under the care of the chest physicians. Breathlessness was, however, the symptom that caused most distress to the patient, nurse, and doctor. In 18 patients who complained of pain 11 described it as moderately or severely distressing. Ten of these 11 patients were receiving opiate medication but not an adequate dosage or interval between dosages.

Ten of the 16 patients with pressure sores developed them after admission to hospital. Nine patients had more than one sore, seven of whom had a non-malignant disease. Constipation, nausea, vomiting, and incontinence were not particular problems.

Nineteen patients recognised depression as a problem. Six patients who felt extremely depressed had all reported several distressing symptoms. Anxiety was experienced by patients who did not know their diagnosis. Anger was not an important feature; only five patients reported feeling "moderately" angry.

TABLE I—Summary of symptoms reported by patients to researcher

Symptom	No of patients	Symptom	No of patients
Anorexia	24	Pressure sores	16
Insomnia	23	Constipation	14
Immobility	23	Nausea	14
Malaise	23	Oedema	11
Sore mouth	21	Confusion	9
Cough	20	Incontinence	8
Dyspnoea	18	Vomiting	7
Pain	18	Malodorous wounds	2

RELATIVES

Seventeen of the 20 relatives interviewed were fearful of caring for the patient at home. Pain, breathlessness, lack of general practitioner support, and fear of the patient dying at home or falling over were the most common fears reported. Eight relatives had one or more social service facilities to help them care for the patient at home. Six relatives (particularly tearful at interview) felt that they would have benefited from some help if it had been organised. In four of these cases the patient had been confined to bed because of severe weakness or pain. As a result the relatives felt guilty "because they could not manage to look after the patient at home," and the lack of support had precipitated the admission.

The support of family and friends was of particular value to most of the relatives, and 14 talked often about their situation to those around them. One relative in particular gained a lot of support from the home help. Three relatives occasionally chatted to others. Of the three remaining relatives, who did not talk to anyone, two were the only husbands being interviewed.

All but one of the relatives interviewed knew the patient's diagnosis and seemed to know the seriousness of the patient's illness. This, however, was mostly due to their own observation rather than being informed by the doctor.

The relatives were very "understanding of the pressures" that they thought the nurses and doctors were under, which prevented them from having more time to discuss the patient's illness. Seven relatives (all visiting daily) could not remember speaking to a doctor during this admission. Another five relatives said that they had spoken to a doctor only once. Ten relatives thought that they had been given inadequate information. Eleven relatives said that the patient had mentioned in some way that he or she might die. Most relatives felt they did not know what to say or how to react and generally changed the subject.

Fatigue was the most common emotion reported by the relatives. Depression and anxiety were increased where confusing statements and information about prognosis were proffered, and lack of openness existed

between patient and relative. Anger was generally projected on to various problems, such as the buses, noisy neighbours, and so on.

Discussion

The study succeeded in monitoring both the physical and mental distress of terminally ill patients. Anorexia, sleeplessness, coated or infected mouths, pain, and pressure sores were all seen to be causing prominent distress in over half of the patients. There is little difference between these findings and those in other studies.^{4,7,8}

Opiate medication was being used to try to control pain but usually not in adequate dosages or intervals. Though there is continuing controversy about the pharmacokinetics and clinical effects of morphine and its metabolites,⁹ hospice experience has provided a wealth of empirical data on the effectiveness of morphine when prescribed regularly in adequate dosage. This knowledge has not filtered across into the hospital.

Baines states that anorexia is very common in patients with widespread malignant disease.⁸ In our study it was at least as common in patients with non-malignant disease. Dietary manipulation plays an important non-pharmacological part in the palliation of this distressing symptom. The use of small, visually attractive meals which are specifically seasoned to appeal to the individual patient is rarely achieved in hospital. This is especially so when the patient is placed on a "soft" diet. The need to pay careful attention to mouth care, particularly the treatment of oral thrush, is highlighted, and this may help to improve the sense of taste. Concurrent nausea requires regular antiemetic drugs.

The high incidence of pressure sores bears out the observations of Barton and Barton.¹⁰ Two thirds of the patients in our study developed pressure sores while in hospital. Specific attention to relief of pressure and availability of pressure dispersion mattresses and beds are required. Better pain relief will allow some patients to move around more, but an aggressive policy of frequent turning should not interfere unduly with sleep or the dignity of the final hours.

Including patients who were dying from a non-malignant disease in the study highlighted certain problems such as nausea, anorexia, and pressure sores in this group. It was found that moderate and severe pain occurred as often in these patients as in patients with cancer.

Anxiety and anger were not problems, although anxiety was heightened when patients' relatives were not receiving information about diagnosis and outcome. Though there has been a move to greater truth telling about diagnoses, follow up information and monitoring of how information is received are still lacking.¹¹ The tendency for relatives to passively accept that the pressure on a doctor's time precludes doctors from seeing them further bars effective communication. Turnover of staff compounds this, particularly when information is not passed on to new staff by those who move on. One patient said: "You only just start getting to know and trust the doctor, and then he moves on." During a four month period this patient had seen three different housemen, two senior house officers, and two registrars. This can only exacerbate the tendency to avoid dying patients, which was identified by Schulz and Aderman.¹²

Communication can be improved by keeping records of the information that is given to and received from patients and relatives. Hospices often use a special coloured sheet of paper in the medical notes for details of conversations about diagnosis and prognosis. This may also encourage better contact with relatives before and after death. Relatives should be given the chance to speak with the doctor on each admission, preferably within the first few days, so that they can receive updates about the patient's condition and are not left to "guess." Such contact should encourage greater access to information and sharing fears, thereby reducing the risk of mental and physical breakdown during bereavement.

The other interesting feature shown by this study was that all but two of the patients who knew their diagnosis referred to death and dying during conversations with their close relatives. This should remind us that patients cannot avoid the issue of dying even if we do.

TABLE II—Referral pattern from specialists, 1984-7

Specialty	1984 (n=121)	1985 (n=164)	1986 (n=255)	1987 (n=285)
Oncology	4	7	19	15
Radiotherapy	12	22	40	81
Surgery	31	72	135	103
General medicine	74	63	61	86

Reason for referral:

Symptom control 179 patients
 Psychological support 59 patients
 Home care support 32 patients
 Other (hospice advice, dressings, staff support) 12 patients

As a direct result of this study the City and Hackney Area Health Authority set up a working party to look at the feasibility of having a specialist, multidisciplinary team to advise about symptom control and to support the terminally ill patient and his or her family. The creation of a specific unit for the terminally ill was rejected in favour of "working alongside" the consultants in charge when invited to. The team would thus be able to disseminate their skills more widely to all grades of doctors and nurses. Being an advisory service enables consultants to "use" the team whenever there is a need without waiting until a decision has been made to discontinue curative treatment. The team now has a complement of one full time doctor, three full time nurse specialists (two based at our hospital, one based at Hackney/Homerton Hospital), one part time social worker, and one secretary.

The numbers of patients referred to the team have gradually increased (see table II), showing that the team is accepted by most of

the consultants. The main reason for referring most patients continues to be palliation of symptoms from advanced cancer (see table II). The team is concerned with half of the total number of patients who die of cancer at this hospital. The number of patients who are referred with non-malignant disease is increasing.

A more objective measure of the effect of the team is the dramatic reduction in the number of complaints relating to "terminal care." In 1983, 14 complaints were received from relatives who had been dissatisfied with the care of close relatives (8.6% of 163 complaints received). In 1985—one year after the introduction of an advisory service—complaints about the care of the dying in hospital had dropped to five, and in 1987 there were two.

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Syringe exchange schemes for drug users in England and Scotland

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Abstract

In 1987 experimental schemes for distributing injecting equipment to intravenous drug users to help prevent the spread of the human immunodeficiency virus were started by the government. After six months the schemes were found to have been reasonably successful in attracting clients but were less successful in keeping them. It has been shown that equipment can be distributed to drug users on an exchange basis. Many of the clients who were attracted to these schemes had had no treatment or other help for their drug problems.

Introduction

In April 1987 the government launched pilot schemes to attempt to reduce the spread of infection with the human immunodeficiency virus (HIV) among intravenous drug users by making injecting

equipment available to them, together with advice on drug use and safer sex. These are commonly known as "syringe exchange schemes." The government took this step because of reports of high rates of HIV infection among some groups of intravenous drug users. The highest known rates of HIV antibody seropositivity in intravenous drug users are in Edinburgh, where between 1983 and 1985 half of the 164 heroin users tested seropositive.¹ In other large cities known rates are much lower. In Glasgow 4.5% was recorded in 1985,² and rates of between 0 and 10% have recently been reported in different English cities.^{3,4} While the potential spread of infection with HIV is a serious problem, in many areas there is time to try to prevent it.

In England the Department of Health and Social Security invited drug agencies to set up pilot schemes for one year, offering some financial support for that first year. In Scotland the Scottish Home and Health Department asked health boards to set up the schemes. The DHSS asked potential participating agencies to provide (a) injecting equipment on an exchange basis to drug abusers who were already injecting and unable or unwilling to stop; (b) assessment of and counselling for clients' drug problems; (c) advice on safer sex and counselling on HIV testing. The Scottish schemes included medical staff.

Research design

We were asked by the DHSS and the SHHD to monitor (a) the implementation of the schemes by looking at the organisation of schemes, nature of treatment and counselling provided, numbers

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