The quality of care and symptom control - the effects on the terminal phase of ALS/MND

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Abstract

The quality of care in the terminal phase of ALS/ MND depends critically on the palliative care provided throughout the disease process. A retrospective review of 52 patients shows that patients with multiple symptoms and care needs can be cared for, and die, at home. To ensure that the care of patients is co-ordinated and allows patients and family to be cared for where they wish, a team approach is required . A co-ordinated team approach, involving health care, social services and voluntary groups, is described.

Keywords: Palliative care; Symptom control; ALS/MND

Introduction

The total care of a patient with ALS/ MND needs to be carefully co-ordinated, and the care in the earlier stages of the disease can be crucial in ensuring that the terminal stages and the death of the patient are as good as possible. Palliative care can, and should, be provided for patients with ALS/MND from the time of diagnosis, as there is at present no curative treatment.

Palliative care can be defined as:

> "The active total care of patients whose disease is not responsive to curative treatment, where the control of pain, of other symptoms and of psychological, social and spiri-tual problems is paramount, and where the goal is the achievement of the best quality of life for patients and their families. "
>
> (World Health Organization, 1990)

The aim is to consider the total care of the patient and family and the many different problems faced during the illness, especially the physical problems, including the symptoms faced by the patient and other aspects of care such as mobility and comfort; the emotional aspects of care, including the worries and fears ; the social aspects of the care of the patient and their family; and the spiritual aspects and concerns of the patient, including the concerns about the meaning of life. There may be no easy answers but the fears and concerns of the patient can at least be heard and shared (Oliver, 1993, 1994).

Palliative care starts at the time of diagnosis and can co-exist with other care, such as inclusion in drug trials. The aim is to help the patient to live as full a life as possible.

At the Wisdom Hospice between 1985 and 1995, 52 patients have died of motor neurone disease, excluding patients from outside the area and patients dying within a week of referral. The Wisdom Hospice is able to offer integrated care for patients, primarily with advanced cancer but also for people with ALS/ MND. This care may be inpatient care in the hospice with 15 beds; at home, with advice and support of the Domiciliary Team nurses working in collaboration with the Primary Health Care Team of General Practitioner and Community Nurse; or in day care, providing respite care. At any one time about eight people with ALS/MND are supported at home. Bereavement care for families after the death of the patient is also provided.

During this 10-year period 25 (48%) of the patients have died at home and 27 (52 %) have died in the hospice. A retrospective study of notes has been performed to look at characteristics of patients and medication used in the two areas of care.

Results

Of the total population of 52 patients, 36% had presented with symptoms in the arms, 28% with changes in the legs and 36% with bulbar symptoms. 62% were male, with a mean age of 67.7 years and 38% were female, with a mean age of 62.7 years. 56% of the patients were over 65 years old and 81% were married. The average duration of the disease from the first symptom to death was 26 months, with an average delay to diagnosis of 9 months.

The patients who died at home were more often male - 72% compared to 52% of patients in the hospice; and were more likely to be married and living with a partner - 92%, compared to 70% in the hospice. Bulbar symptoms were not as common as the mode of presentation for patients dying at home - 24% bulbar presentation, 44% arms and 32% legs, compared to the presentation with bulbar changes for 48%, arm changes for 30% and leg symptoms for 22% for patients dying in the hospice. The symptoms reported by the two patient groups are shown in Table I. The patients dying in the hospice suffered more dysarthria, dysphagia, cough, emotional lability and insomnia, reflecting the higher incidence of bulbar presentation.

From the hospice notes it was possible to accurately assess the medication given to patients dying in the hos-pice, but the records were less clear for patients at home, as other health care professionals were also visiting the patient and may have prescribed or given medication without recording this in the notes. However the medication, as recorded, is shown in Table 2.

Morphine was given to a larger proportion of patients in the hospice, and this may reflect increased use or may reflect better recording of the use of medication. The route of administration was more likely to be parenteral in the hospice group of patients, either by single injection or continuous subcutaneous infusion, and this would seem to be related to the greater problems of swallowing from bulbar involvement.

The doses of opioid medication were not large, the mean dose at home being 90 mg oral morphine equivalent/24 hours, and the mean duration of use at home was 240 days.

48% of this patient group were able to die at home. The other 52% of the patients died in the hospice but the majority of the time of the care under the hospice services was at home, and on average 82% of the care was at home.

Discussion

Other surveys of the terminal stages of ALS/MND have primarily reported the in-patient care of patients - 92% of patients dying under the care of St. Christopher's Hospice in London died in the hospice (Saunders et al., 1981; O'Brien et al., 1992). The results presented here show that people with ALS/MND can be cared for at home, even when there are multiple symptoms and a need for medication.

The results for the overall population are similar to other population surveys (Rosen, 1978; O'Brien et al., 1992). It would appear that the patients who required admission to the hospice for the terminal period were more likely to be female and living alone, unmarried, divorced or widowed. These patients had presented more commonly with bulbar symptoms and suffered with more severe symptoms related to these bulbar changes. Patients dying at home were more likely to be male and supported by a partner who could provide care at home.

The use of opioid medication was similar in patients at home and in the hospice. The control of medication was usually with the same hospice doctors, and the indications for the use of opioids were the same at home and in the hospice. The doses are higher than in other surveys - the mean oral morphine dose was 90-100 mg/24 h, whereas at St. Christopher's Hospice, where 88% received an opioid, the mean dose was 30 mg/24 h as oral morphine equivalent. Opioids were used for long periods of time - up to three years, with a mean of 240 days for patients dying at home. These results confirm that oral opioids do not necessarily hasten death but by controlling symptoms and relieving distress can allow patients to live full lives (Oliver, 1993). The lower doses of morphine for patients at home, who tended to deteriorate more quickly in the terminal stages, also argues against death being hastened by opioid medication.

To allow patients to remain and die at home, an interdisciplinary approach is necessary and the care needs to be carefully co-ordinated between the many agencies involved. These include the General Practitioner, community nurse, Social Services carers providing personal and social care, the services from the hospice (home care nurses, day care, hospital specialist nurses, in-patient care), night nursing services, the Motor Neurone Disease Association (providing advice and support, equipment and financial help), and family and friends. It is essential to ensure that all these services are able to help and support the patient and family and do not hinder the patient's own coping strategies. This care must be co-ordinated, and in the Medway area a Clinical MND Team has been formed as a joint venture between the Wisdom Hospice, the Community Physical Disability Team, the Motor Neurone Disease Association and the Social Services Occupational Therapy Bureau to improve communication among all the professionals involved in the patients' care and to co-ordinate the care that is given. The Team meets monthly and all new referrals are discussed, with the patient's permission, and the care planned. If possible a key worker is agreed to co-ordinate the care. The meeting also offers the chance for mutual support for the professionals involved in the care of patients with ALS/MND.

With a co-ordinated care approach it is often possible to support patients in their own homes. However, admission to the hospice was necessary for some patients, when: there was no close family or carers; the symptoms, particularly related to bulbar dysfunction, were difficult to control; the home circumstances were less satisfactory for care at home; the carers were unable to cope physically or emotionally; or the patient and family expressed a wish for hospice care. However, the need for admission was often only for respite care or terminal care in the last few days and weeks and the majority of care was at home, with the extra support of the wider professional team.

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Table I
Symptoms experienced by patients

	Patients dying at home	Patients dying in the hospice
Weakness	24 (96%)	25 (93%)
Dysphagia	22 (88%)	25 (93%)
Dyspnoea	22 (88%)	22(81%)
Pain	19 (76%)	19 (70%)
Weight loss	17 (68%)	20 (74%)
Dysarthria	15 (60%)	22(81%)
Constipation	14 (56%)	14 (52%)
Cough	11 (44%)	14 (52%)
Poor sleep	6 (24%)	9 (33%)
Emotional !ability	6 (24%)	8 (30%)
Drooling	6 (24%)	7 (26%)

Table 2
Medication received by patients

	Patients dying at home	Patients dying in the hospice
Oral morphine	13 (52%)	23 (85%)
Diamorphine by injection	8 (32%)	19 (70%)
Diamorphine by continuous subcutaneous infusion by syringe driver	5 (20%)	16 (59%)
Diazepam	15 (60%)	21 (78%)
Parenteral hyoscine hydrobromide	8 (32%)	14 (52%)
No parenteral medication	13 (52%)	8 (30%)