# An audit of palliative care in dementia

MARI LLOYD-WILLIAMS, MBChB, *Department of Psychiatry, University of Leicester, Leicester General Hospital, Gwendolen Road, Leicester LE5 4PW, UK*

LLOYD-WILLIAMS M. (1996) *European Journal of Cancer Care* **5**, 53–55
**An audit of palliative care in dementia**

A retrospective case note audit was conducted in order to determine the most prevalent symptoms in terminal dementia and to assess the palliation given. Seventeen case notes were audited. Pain and dyspnoea were the most common symptoms. The palliation and treatment of constipation and oral candidiasis was within current accepted practice. Palliation of other symptoms were inadequate compared to current accepted practice. There appeared to be a reluctance to prescribe opiate analgesia, and when this was prescribed the doses were not modified to achieve full pain or symptomatic relief. Many patients were unable to take medication orally, but syringe drivers were not used. The conclusions include the need for education of both nursing and medical staff as to the current principles of palliative care.

*Keywords:* dementia, audit, palliative care, education.

## INTRODUCTION

Dementia is a progressive terminal illness, but its progression varies. The prognosis for a patient with such an illness may range from 2 to over 15 years. Although many patients are cared for at home during the early stages, a large proportion of patients are admitted to nursing homes or long-stay hospital wards as the disease progresses.

The majority of palliative care teams do not currently include the care of the patient with end-stage dementia in their remit. Several studies, for example, those by Luchins & Hanrahan (1993) and Ryan (1989), have emphasized the need for the implementation of good palliative care in this group of patients.

The following is a retrospective case note analysis which was carried out in order to determine what were the predominant symptoms requiring palliation in patients with end-stage dementia and to assess the palliation given.

## METHODS

The case notes of the most recent 25 deaths of patients with end-stage dementia who were on a long-stay psychogeriatric ward at the time of their death were obtained. The criterion for inclusion in the audit was that the death certificate should contain either dementia, Alzheimers disease or multi-infarct dementia as a contributory cause of the death.

Information was obtained as to the age of the patient, length of diagnosis, length of admission preceding death and the cause of death.

The main symptoms during the terminal phase of the illness which were recorded in the case notes were noted, and further information was obtained from the case notes, nursing records and medicine charts as to whether an attempt has been made to palliate the symptoms.

## RESULTS

Despite extensive searches, it was not possible to locate five sets of notes, and a further three patients had died suddenly and were therefore excluded from the study. Of

the 17 case notes audited, 14 were female and three were male. The average age at time of death was 83.2 years.

The length of time since diagnosis varied from 14 months to 16 years, with a mean duration of 3.6 years. The mean admission period prior to death was 10 months, ranging from 12 days to 4 years.

The cause of death was recorded as bronchopneumonia in 13 cases, congestive cardiac failure in two cases, and gastro-intestinal haemorrhage and disseminated carcinoma of the breast in two further cases.

The main symptoms recorded during the terminal illness, i.e. the last 2 weeks preceeding death, are given in Table 1. Where pain was noted as a symptom, it was not always possible to elicit the exact cause of the pain from the case notes, but four patients were noted to have pressure sores, two had recent fractures and seven were known to have osteoarthritis. The patient with carcinoma of the breast was known to have bone metastases.

**Table 1.** Symptoms recorded during terminal episode

| Symptoms | Number ($n = 17$) |
|---|---|
| Shortness of breath | 12 |
| Pain | 10 |
| Pyrexia | 7 |
| Oral thrush | 2 |
| Constipation | 2 |
| Vomiting | 1 |
| Symptoms not noted | 1 |

In 14 cases antibiotics were given for bronchopneumonia and continued for 1–4 days prior to death. Anti-emetics were prescribed as required. Oral thrush was treated with regular oral anti-fungal agents and laxatives prescribed for constipation were administered on a regular basis.

Narcotic analgesics were prescribed in six cases, but in only two cases was a regular prescription written on the drug card; the timing of administration was once daily. Where narcotic analgesics were prescribed regularly, there was no provision for modifying the dose if the symptoms escalated and there was no evidence of a titration of dosage being carried out. The dosage of opiates given varied. On the regular prescription, 5 mg of morphine once daily was prescribed, and the as-required dosage varied from 5 to 30 mg and the morphine could be given either orally, rectally or intramuscularly. Laxatives were not routinely prescribed with opiates.

There was no record in any of the case notes as to the degree of palliation achieved for any of the symptoms listed in Table 1, but comments in the notes such as 'still appears to be in discomfort' suggest that in several cases palliation was inadequate.

Despite the fact that it was noted that the patients were unable to take medication orally for the last 48–72 hours, syringe drivers were not used.

The nursing care of the patients, e.g. regular turns, use of special mattresses, mouth care, was documented in 85% of cases.

## DISCUSSION

Although this is a small case note study, a number of important points in the care of the terminally ill dementia patient emerge.

The majority of deaths resulted from bronchopneumonia and, in 14 cases, antibiotics were administered. The use of antibiotics in such situations is, however, debatable as studies by Fabiszewski *et al.* (1990) have indicated that the use of antibiotics does not alter the outcome in patients with advanced dementia. A study by Hurley *et al.* (1993) reported that aggressive medical treatment of infections had a limited effect on the mortality rate, and that patients treated palliatively had lower discomfort scores, and showed higher utilization of analgesics and narcotics.

The management of symptoms such as constipation and oral thrush appear to have been appropriate, but the palliation of pain, pyrexia, shortness of breath and vomiting was variable.

The use of regular simple anti-pyretics, e.g. paracetamol, was not initiated for the symptomatic relief of high fevers, and other methods to improve the patients comfort, for example, the use of fans, were not employed. Vomiting was listed as a symptom, but the use of regular anti-emetics was not initiated and it seemed that anti-emetics were only administered after the patients had vomited on a few occasions. Regular anti-emetics, prescribed before meals can also help to alleviate nausea and would be especially beneficial in this group of patients who may be unable to describe their symptoms.

Non-steroidal anti-inflammatory drugs when prescribed regularly can be useful in the palliation of bone pain, but none of the patients in this study were given non-steroidal preparations. The most common symptoms noted were pain and dyspnoea. From the case notes, it seemed that there was a reluctance to prescribe opiates to palliate these symptoms and there were comments, e.g. 'withhold morphine as it may affect respiratory rate' and 'only give morphine if really necessary', in the case notes. In the terminal care situation, it is known that morphine in adequate doses can reduce the sensation of breathlessness and greatly improve the patients comfort. When opiates were prescribed, the usual practice of 4-hourly prescribing


 

with titration of the dose and provision of an appropriate dose on the as-required prescription was not employed.

It is apparent from this study that both medical and nursing staff caring for patients with end-stage dementia were unsure of current palliative care practices and hence, in many cases, inadequate palliation was administered. In a survey of doctors and nurses approaches to terminal care in old age psychiatry (Richards & Lindesay, 1993), 42% reported being unsure about how to manage pain relief in dying patients.

Nurses working on long-stay psychiatric wards have usually obtained the qualification of Registered Mental Nurse and do not receive any special training in the care of the terminally ill during their training. Similarly, psychiatrists do not receive teaching in this area as part of their postgraduate training.

As the majority of elderly patients with dementia who are on long-stay psychiatric wards remain on these wards until their death, it would seem appropriate if at least one member of nursing staff was offered some training in the principles of palliative care. The majority of career psychiatrists spend a period of time working in old age psychiatry, but at present there is little or no formal teaching on palliative care.

The conclusions from this study are that, at present, terminally ill dementia patients are not being given adequate or appropriate palliation for their symptoms. Attempts should be made to equip both medical and nursing staff caring for the elderly patient with dementia with the knowledge to provide appropriate palliation of symptoms.

It is unlikely that palliative care services will ever be able to encompass the care of everybody with a terminal illness. However, the principles of good symptom control can and should be acquired by all professionals working in all disciplines.

In order to complete the audit cycle it is intended to provide staff working on long-stay psychogeriatric wards with teaching on the palliation of symptoms. It is also the intention to provide junior medical staff with information regarding the palliation of symptoms in terminal dementia, and to encourage both medical and nursing staff to contact local expertise, e.g. the local hospice, if they are faced with a difficult situation.

The audit will be repeated after the above has been implemented to establish if there has been an improvement in care.

**Acknowledgements**

I would like to thank the department of Psychiatry at Leicester General Hospital for their support with this study.

**References**

Fabiszewski K.J., Volicer B. & Volicer L. (1990) Effect of antibiotic treatment on outcome of fevers in institutionalised Alzheimer patients. *Journal of the American Medical Association*, **263**, 3168–3172.

Hurley A.C., Volicer B., Mahoney M.A. & Volicer L. (1993) Palliative fever management in Alzheimer patients—quality plus fiscal responsibility. *Advances in Nursing Science*, **16**, 21–32.

Luchins D.J. & Hanrahan P. (1993) What is the appropriate health care for end stage dementia? *Journal of the American Geriatric Society*, **41**, 25–30.

Richards J. & Lindesay J. (1993) Terminal care in old age psychiatry: a survey of professional's attitudes and approaches. *Psychiatric Bulletin*, **17**, 207–209.

Ryan D.P. (1989) The first international conference on the palliative care of the elderly. *Journal of Palliative Care*, **5**, 40–42.