

Research Study

Can multidisciplinary guidelines improve the palliation of symptoms in the terminal phase of dementia?

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Abstract

Dementia is a progressive terminal disease. More than 95% of patients will require 24-hour care either in long-stay hospital wards or in nursing homes at the end of life. There are many issues in the care of patients with dementia that parallel palliative cancer care, but relatively few patients with dementia currently access palliative care. Following an initial audit that found that many patients dying with dementia had symptoms that were not palliated, multidisciplinary guidelines were developed jointly by medical and nursing staff working in psychiatry for older people, together with pharmacy and palliative care staff. Following the implementation of guidelines, there was a significant decrease in the prescribing of antibiotics in the last 2 weeks of life and patients were much more likely to be prescribed analgesia, including opiates. This small study suggests that when developed collaboratively, multidisciplinary guidelines can have a positive impact on palliative care for non-oncology patients.

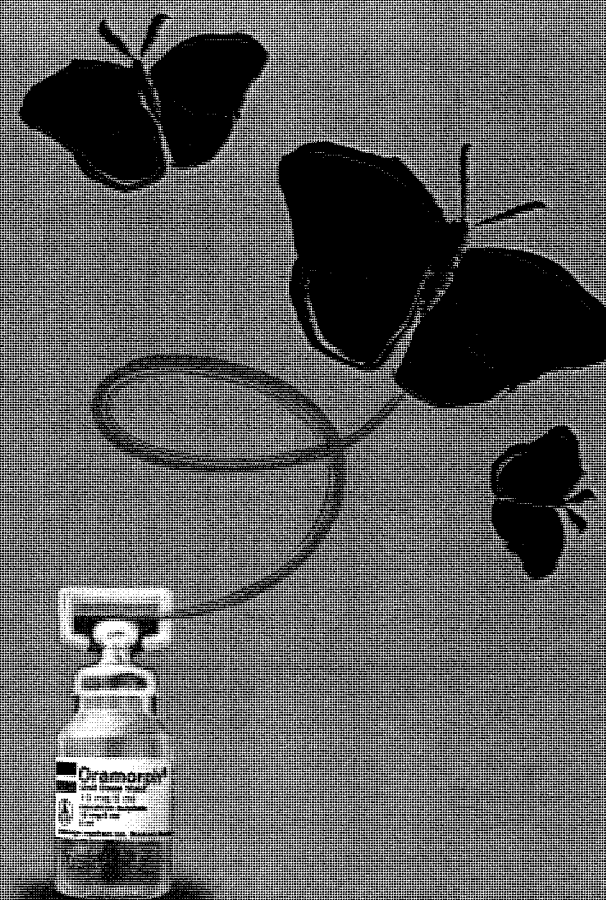
Dementia is recognized as a progressive terminal illness for which there is currently no cure. The incidence of the disease increases from 1 in 1000 in those below the age of 65 years to one in five in those over the age of 85 years – as the number of older people increases, dementia will become more prevalent (Luchins and Hanrahan, 1993). During the early stages of the illness, the majority of patients are cared for in the community by lay carers, but as it progresses, more than 95% of patients require 24-hour care either in long-stay hospital wards or in nursing homes (Luchins and Hanrahan, 1993). There are many issues in the care of patients with dementia that parallel those in palliative cancer care.

The communication of a diagnosis of an incurable disease is difficult. Research has shown that, although the majority of relatives wished to be told if they themselves developed dementia, they did not wish this to be conveyed to the patients (Maguire et al, 1996). This can be compared to the conveyance of a diagnosis of cancer 30 years ago when it was often held that being truthful with patients would precipitate anxiety

and depression. In reality, many patients in the early stages of dementia are fully aware of their cognitive impairment and withholding such information is likely to do more harm. Sensitive communication of the diagnosis can have benefits, as patients may be able to participate in decisions regarding their future health care and also those regarding life-sustaining treatment, before their condition deteriorates and they are rendered incapable of making such decisions themselves (Meyers, 1997). The emergence of new therapies, e.g. donepezil, although palliative, further supports the need for patients to be told their diagnosis (Mechanic, 1997). Patients may prefer not to take certain therapies if they fear these could prolong a state of severe dementia.

It is widely accepted that the principles of palliative care are applicable to patients with non-malignant disease. A case report by the daughter of a patient dying of dementia made a plea for palliative care services to include these patients (Abuolon, 1998). Several research studies (Ryan, 1989; Fabiszewski et al, 1990; Luchins and Hanrahan, 1993; Hanrahan and Luchins, 1995) emphasized the need for the implementation of good palliative care for patients with dementia and illustrated that the palliation of symptoms leads to improved comfort and quality of life. The majority of palliative care teams continue to focus their care on patients with cancer and, despite the development of community and hospital palliative support teams, it seems unlikely that they will be able to care for all patients requiring palliative care in the future (Shuster, 2000). It is imperative, therefore, that teaching and education about palliative care are developed together with the key providers of care, and that such initiatives are learner-based and needs-led.

This article describes the development and implementation of guidelines for



Twist to
relieve severe pain

Oral
Oramorph
Unit Dose Vials

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caring for patients with dementia on acute psychogeriatric wards.

Background

An initial audit involved a retrospective survey of palliative care given to patients dying of end-stage dementia on long-stay wards (Lloyd-Williams, 1996; McCarthy et al, 1997). This revealed that patients had many symptoms, e.g. pain, dyspnoea and pyrexia, for which no palliation was given and highlighted the widespread use of parenteral antibiotics in the last days and weeks of life, and the infrequent use of analgesia (Figure 1).

Following this study, key members of the medical and nursing staff working on long-stay wards, together with a palliative care doctor and pharmacy staff, developed a series of simple guidelines on the stepwise management of the most common symptoms occurring in the last weeks of life, e.g. pain, dyspnoea and pyrexia. The guidelines focused on these areas, as they highlighted

in the original audit, and also on other issues raised by nursing staff, including pressure care, obtaining equipment and where to obtain specific advice. The guidelines were made available to all medical and nursing staff and were included in a handbook for junior doctors that was issued to all new medical staff working on the long-stay unit. The palliative care offered to patients dying of dementia was re-evaluated a year later to determine whether such multidisciplinary guidelines could have an impact on their care.

Method

A retrospective study of all death occurring in the long-stay unit of a large psychiatric hospital was undertaken for the 12 months following the implementation of guidelines. The unit, which consisted of a number of long-stay wards, was the same unit as audited previously and data were collected in the same manner. The medication cards and case notes were obtained for each patient who had died – those patients dying from a sudden unexpected event were excluded from the study. Information was collected on age, sex, cause of death, symptoms documented in both medical and nursing notes, drugs administered during the last 2 weeks of life and the routes of administration used. Other than the formulation and implementation of the guidelines, no factors that could have caused the observed changes in patient care were identified.

Results

Twenty-seven deaths (20 female and 7 male) were included in this study. The cause of death was stated as bronchopneumonia for 26 patients and congestive cardiac failure for one patient. The median age at death was 82.7 years (69–94 years) and the time from admission to death was a median of 9.2 months (ranging from 3 weeks to 14 months).

Following the implementation of guidelines (Figure 2), patients who were reported as being in pain were initially commenced on non-steroidal anti-inflammatory drug (NSAID) suppositories and opiate syrups. Opiates were prescribed regularly in 13 of the 27 patients (48%) – these patients were prescribed immediate release (IR) morphine 4-hourly for the palliation of pain or dyspnoea (caused by bronchopneumonia) (Figure 3). Two patients who were distressed and unable to take oral medication were commenced

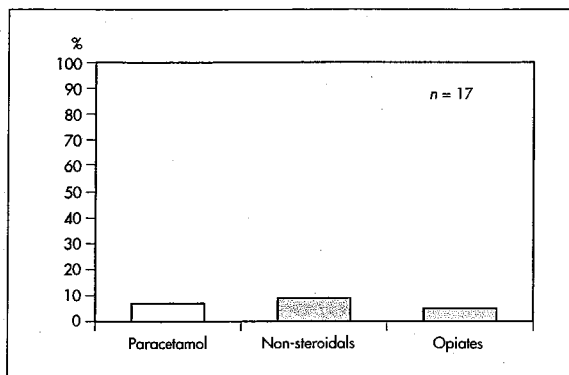


Figure 1. Use of analgesia in patients with dementia before guidelines.

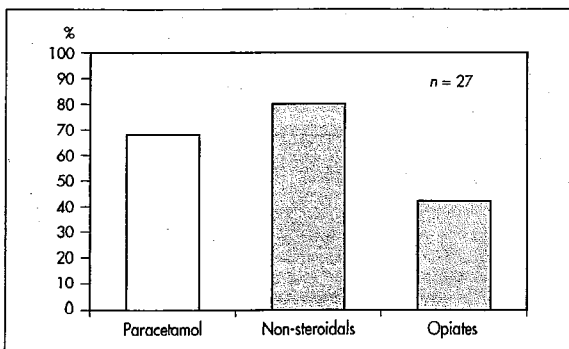


Figure 3. Use of analgesia in patients with dementia after implementation of guidelines.

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FIGURE 2. GUIDELINES FOR MANAGEMENT OF PATIENTS WITH END STAGE DEMENTIA

PAIN/DISCOMFORT

General measures

- Think of treatable causes, e.g. constipation, full bladder, pressure sores
- Use oral route where possible and always prescribe regularly, not as required
- Initially use co-proxamol, e.g. 2 tablets four times daily
- If pain still a problem consider non-steroidal anti-inflammatory drugs, e.g. diclofenac 50 mg three times daily orally, or 100 mg per rectum

Opiates

- Dosage – start with low dose and titrate, e.g. 5 mg 4-hourly with same dose for use as required
- If patient appears in pain when turning, for example, give extra dose half an hour before procedure
- Always ask or prescribe diamorphine 2.5–10 mg as required so that analgesia can still be given if oral route unavailable

SYRINGE DRIVERS

- Each unit now has access to a syringe driver and all doctors and nursing staff should be familiar with the location of the driver and how to set up an infusion.
- When converting from oral to subcutaneous opiates remember to divide the total oral dose by three, e.g. 60 mg oral morphine in 24 hours = 20 mg diamorphine in syringe driver.
- If patient is agitated add either midazolam 10–20 mg per 24 hours or haloperidol 5–15 mg per 24 hours.
- If you need any advice regarding symptom control, please contact the unit liaison nurses or Drs X, Y, Z, who have a special interest and will assess the patients.

VOMITING

- Regular antiemetics relieve or can help nausea and vomiting
- Haloperidol 1.5 mg three times daily or 5 mg at night (orally or subcutaneously) can help if vomiting is the result of infection

AGITATION

- Think of cause, e.g. full bladder, pain
- Midazolam 2.5–10 mg subcutaneously, haloperidol 5–10 mg oral or subcutaneously,

- Thioridazine 10–50 mg three times daily orally can help reduce agitation

ORAL CARE

- Oral thrush can be painful and debilitating
- Use nystatin 1 ml four times daily or fluconazole 50 mg once daily

CONSTIPATION

- Laxoberal 5–15 ml once or twice daily is recommended for constipation in debilitated patients

DYSPNOEA

- Most common cause is bronchopneumonia. There is no evidence that using antibiotics in end stage dementia is helpful or improves patients' comfort or prolongs the quality of life.
- Good palliation of symptoms includes:
 - Paracetamol 1 g orally or per rectum four times daily for pyrexia
 - Fan and regular nursing care for fever
 - Saline nebuliser may encourage expectoration and improve patient's comfort
 - Oral morphine 5 mg 4-hourly can reduce sensation of breathlessness and improve patient's comfort.

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on syringe drivers. There was a significant decrease in the prescribing of antibiotics in the last 2 weeks of life – six patients (22%) in this study were prescribed antibiotics compared to fourteen (82%) ($P=0.001$) in the initial study (Figure 4). Paracetamol, as an antipyretic was prescribed for 20 patients (74%) although this was only prescribed regularly in eight cases. There were references in the notes that advice was obtained from both the local hospice and hospital palliative care team for symptom control.

Discussion

This small study suggests that guidelines developed by a multidisciplinary team can improve palliative care in a setting where it may not previously have been recognized or practised. Great efforts were made to involve all staff in the initial audit – staff were very keen to ensure that better care was delivered for patients and to be involved in the development of guidelines – a factor that has probably been crucial to their implementation and apparent success.

The initial audit suggested that patients developed pain from pressure sores and stiffness and it was believed that the use of NSAIDs would be appropriate palliation especially as these can be administered in the form of suppositories – a route not dependent on the patients' level of awareness. Immediate release opiates were suggested for inclusion in the guidelines as they would be easier to administer and titrate. Oral medication can be a problem as many patients with dementia tend to 'pouch' food or fluids and have difficulty swallowing. Only two patients were commenced on syringe drivers. This was fewer

than expected and possibly indicated the reluctance of some medical and nursing staff to use this route.

There was much debate as to the use and value of antibiotics – nursing staff generally felt they were administered inappropriately and were particularly concerned regarding the use of intramuscular administration and the discomfort this caused to patients. It was also felt that where possible relatives should be included in the decision-making process regarding whether it was advisable to use antibiotics in the event of patients' deterioration. The second audit suggested that relatives were consulted, however, in many cases there were no available relatives to consult. Several members of nursing staff stated that they felt medical staff were unwilling to switch to a palliative approach and the provision of guidelines helped to reinforce their case for such an approach to be used. It was apparent from the notes that the change agents and those who facilitated the implementation of the guidelines were the nursing staff. The use of guidelines appeared to contribute to the decision-making process when there was a possible ethical dilemma.

Such barriers to appropriate palliative care for patients with dementia have been described in other studies (Ahronheim et al, 2000; Volicer, 2001). It has also been suggested that patients with dementia were significantly more likely to be prescribed antibiotics than patients with advanced cancer (Ahronheim et al, 1996). The use of a specific protocol to assess discomfort in patients with dementia has been reported and was found to increase the use of analgesia (Kovach et al, 1999). Although no specific protocol for assessment of symptoms was used in this study, the case note review revealed that staff also relied on behavioural symptoms that signal pain, e.g. tense body language, fidgeting or perseverant verbal outbursts when caring for such patients. The notes and direct observation of practices on the ward suggested that nurses had developed a very intimate caring relationship with their patients over considerable periods of time and were able to communicate and calm the patients and were also very sensitive to any changes in behaviour that may have been suggestive of pain or distress. Tools have also been developed for the assessment and evaluation of end of life care in dementia looking at relatives' views of care (Volicer et al, 2001).

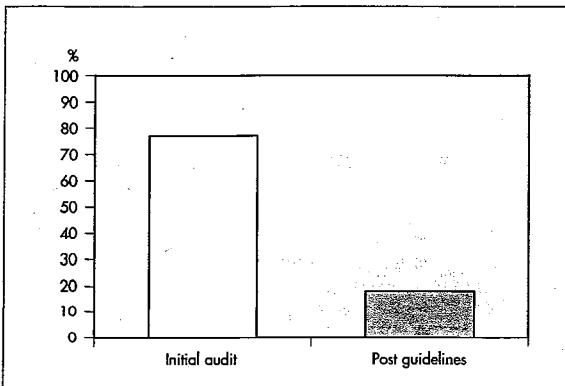


Figure 4. Use of antibiotics – oral and parenteral in last week of life.

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Over the years, it has been learnt in palliative cancer care that just because something can be done it does not mean it should be done and that at times the best treatment is no treatment. Palliative care teams support families both during the illness and in the bereavement and are not afraid of facing the challenges of difficult ethical and often highly emotional decisions. Palliative care for patients with non-malignant disease is already an issue (von Gunten and Twaddle, 1996; Chilver, 2002). It is unlikely that existing palliative care teams can care for all patients who require palliative care and, indeed, it may not be appropriate for them to do so. However, there is a need to develop partnerships in care, to be more proactive and to look critically at which skills and knowledge will be useful for others if they are to provide palliative care within their own settings. A report by the National Council for Hospice and Specialist Palliative Care Services (1998) and a later one in collaboration with the Scottish Partnership Agency (2000) also conclude that partnerships are needed in order to develop and implement palliative care for these groups of patients.

The findings of this study support the use of guidelines in improving palliative care for non-oncology patients and suggest that when developed collaboratively they can contribute greatly to the improved care of patients dying from dementia.

KEY WORDS

- Dementia
- Palliative care
- Multi-disciplinary care
- End-of-life care
- Guidelines

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