

1. The FOOD Trial Collaboration. Routine oral nutritional supplementation for stroke patients in hospital (FOOD): a multicentre randomised controlled trial. *Lancet* 2005; 365: 755–63.
2. The FOOD Trial Collaboration. Effect of timing and method of enteral tube feeding for dysphagic stroke patients (FOOD): a multicentre randomised controlled trial. *Lancet* 2005; 365: 764–72.
3. Spiegelhalter DJ, Abrams KR, Myles JP. *Prior Distributions in Bayesian Approaches to Clinical Trials and Health-Care Interventions*. Chichester: John Wiley & Sons Ltd, 2004, 139–80.

doi:10.1093/ageing/afj028

Published electronically 18 January 2006

Differences in care received by patients with and without dementia who died during acute hospital admission: a retrospective case note study

SIR—Dementia is a malignant and ultimately fatal condition, yet may not be viewed as such [1]. One-third of patients aged between 75 and 84 years with Mini Mental State Examination (MMSE) [2] scores of 19–23 will die within a year [3]. The acute admission of a person with dementia to the general hospital setting increases mortality even further and over half of patients with moderately severe dementia (MMSE cutoff 17/18) admitted with hip fracture or pneumonia will die within 6 months [4]. The incidence of dementia from all causes increases with age, the number of older people is increasing and therefore more patients with dementia will be admitted to, and die on, acute hospital wards. Little is known about the experience of dying dementia patients in the acute hospital setting, although a recent Royal Commission report suggested that they receive sub-optimal care [5] and their religious and spiritual needs are neglected [6].

The aim of this study was to retrospectively examine the care received by dying patients with and without dementia on acute medical wards and to identify differences between them. Our hypothesis was that patients who were documented in their medical notes as having dementia would receive similar end-of-life care to those who were not.

Patients and methods

We examined the case notes of patients aged 70 or over who died whilst an inpatient on an acute medical ward from 1 April 2002 to 31 March 2003. One hundred and fifty sets of notes were selected by hospital numbers (using random

number tables). Of these, 122 sets of notes were available and used for the study. Dementia caseness was defined as having a formal diagnosis of dementia (of any type) written in the medical notes. From the notes, we collected demographic information including age at death, gender, type and severity of dementia and religious faith. Abbreviated Mental Test Scores (AMTS) [7] or MMSE scores were noted if they had been performed at any time during admission. We documented the use of painful invasive procedures such as arterial blood sampling and urinary catheterisation using a checklist developed by Morrison *et al.* [8].

End-of-life care was assessed using items from the Liverpool Care Pathway for the Dying Patient [9]; this includes diagnosing that the patient is dying, limiting unnecessary procedures and interventions, and prescribing appropriate palliative medications. It specifically notes the prescription of medications for certain indications such as pain, nausea, vomiting and excessive respiratory secretions. We also noted whether patients were referred to the palliative care team and whether there was any indication that the patients' spiritual needs were assessed by any member of hospital staff during the admission.

Statistical analysis was performed using SPSS (version 11.0). The relationship between dementia status and dichotomous variables was investigated using Fisher's exact test. The Mann–Whitney U test was used for continuous variables. The study was approved by the hospital ethics committee.

Results

Of the 122 patients with available notes, 35 (28%) had a diagnosis of 'dementia' documented, 65 (53%) were described as cognitively intact and 22 (18%) had no mention of the patient's cognitive status. Further analysis was conducted on the 100 sets of notes where cognitive status was documented.

There were no significant differences in terms of age, gender and length of hospital admission between patients with and without dementia. Of the patients whose dementia status was documented in the notes, 44 (44%) had an AMTS performed during their admission and three patients (3%) had an MMSE. Patients with dementia had significantly lower AMTS scores. Of the 35 patients noted as having dementia, nine (26%) had Alzheimer's disease, 10 (29%) vascular dementia, 1 (2%) Lewy body disease and 15 (43%) had no specific diagnosis made. Significantly fewer patients who were documented as having dementia had any mention of their religious faith (40 versus 63%; $P = 0.023$) (Table 1).

Table 1. Demographic data on patients with ($n = 35$) and without ($n = 65$) dementia who died on acute medical wards

	Dementia ($n = 35$)	No dementia ($n = 65$)	<i>P</i> -value
Age at death, mean \pm SD (range)	86 \pm 7 (75–97)	84 \pm 7 (72–102)	0.502
Length of admission, mean \pm SD (range)	18 \pm 17 (1–60)	16 \pm 14 (1–50)	0.117
AMTS scores ^a , mean \pm SD (range)	1.8 \pm 3 (0–7)	6.8 \pm 3 (0–10)	<0.001
Female (%)	24 (67)	35 (54)	0.175
Religion recorded (%)	14 (40)	41 (63)	0.023

^aData only available on 44 of a total of 100 subjects, 16 with dementia and 28 without dementia

Table 2. Management of patients with ($n = 35$) and without ($n = 65$) dementia prior to death

	No. of patients (%) receiving intervention		<i>P</i> -value
	Dementia ($n = 35$)	No dementia ($n = 65$)	
Arterial blood gases	28 (80)	38 (58)	0.024
Nasogastric tube	14 (40)	15 (23)	0.062
Central line	1 (3)	13 (20)	0.014
Ventilation	2 (6)	6 (9)	0.422
Urinary catheter	37 (77)	27 (57)	0.035
Neuroleptics prescribed	5 (14)	5 (8)	0.238
Imminent death diagnosed	13 (37)	33 (51)	0.137
Resuscitation status discussed	33 (94)	56 (86)	0.185
Discuss limiting procedures – professionals	21 (60)	42 (65)	0.404
Discuss limiting procedures – family	21 (60)	35 (53)	0.353
Referral to palliative care	3 (9)	16 (25)	0.042
Spiritual needs assessed	0 (0)	3 (5)	0.270
Palliative medications prescribed	10 (28)	33 (51)	0.026

Regarding medical management (Table 2), significantly fewer patients who were recorded as having dementia had a central line inserted (3% with dementia versus 20% without dementia). Two patients with dementia received mechanical ventilation. The measurement of blood gases was more frequent among patients who were documented as having dementia (80 versus 58%; $P = 0.024$) as was the use of urinary catheters (77 versus 57%; $P = 0.035$) and nasogastric tubes (40 versus 23%; $P = 0.062$). Discussions regarding resuscitation status and limiting procedures (amongst professionals and with family members) occurred with equal frequency in both patient groups. However, referral to palliative care and the prescription of palliative medications was significantly less frequent in patients who were documented as having dementia. Only three patients (3% of the total cohort) had any assessment of their spiritual needs prior to their death documented.

Discussion

Our results suggest that patients who are noted to have dementia may be receiving different end-of-life care to those who are cognitively intact. Although some of this may be related to associated physical problems—incontinence and dysphagia are common in end-stage dementia [10]—other differences are more difficult to explain.

The diagnosis of imminent death, documentation of resuscitation status and discussions regarding limiting medical procedures occurred with similar frequency in both groups. Although there is some evidence that invasive procedures were limited in patients with dementia, i.e. less use of mechanical ventilation and central lines, and therefore that the poor prognosis of patients with dementia was realised to a degree, this did not appear to influence other aspects of the quality of end-of-life care. It was interesting that significantly more patients documented as having dementia had blood gases measured. This may have occurred because these patients are more vulnerable to developing pneumonia secondary to aspiration or malnutrition [11]. Patients with documented dementia received significantly fewer referrals to specialist palliative care and less palliative medication.

This may occur because there are no validated prognostic indicators for patients with end-stage dementia who are suffering from acute physical illness [12–14]. Dementia does not appear to be viewed as a ‘terminal’ disease by carers [1] nor health professionals [15]. This is despite the facts that the mortality risk ratio of mild/moderate dementia is 3.61 compared to 2.01 for neoplastic disease [15], and in older women, dementia carries a relative risk of death greater than that of carcinoma of the gastrointestinal tract [16]. Although there are worthy calls to increase palliative care provision in dementia [17], any development would be based upon a very limited evidence base; a recent systematic review [18] found only one randomised controlled trial.

A large part of good end-of-life care is control of pain; however, pain is poorly managed in patients with dementia. Cognitively impaired patients with fractured neck of femur are prescribed only one-third of the analgesia compared with cognitively intact controls [19]. Untreated pain and discomfort causes unnecessary suffering and behavioural problems. The latter may in turn lead to the inappropriate use of neuroleptic medication and may engender negative attitudes towards patients with dementia from staff [20–22].

Our results indicate that the recording of patients’ cognitive function during admission was inadequate and this is in keeping with previous studies [21, 22]. The admission of an acutely unwell person with dementia to hospital is a critical event. In a recent study, 53% of patients with severe dementia admitted with hip fracture or pneumonia died within 6 months [2]. Thus, it is a vital part of management that cognitive function is recorded.

Very few patients had their spiritual needs assessed or addressed while they were dying, and it was of note that fewer patients with dementia had information documented regarding their religious beliefs. They may be unable to give details regarding their faith [23], and this should be actively sought from relatives or carers on admission.

The methodology used for this study (retrospective case note review) may have led to some bias, as it relies on the quality of documentation in patient case notes. We have no reason to believe that the quality of note keeping may be different if a patient has dementia. The quality of end-of-life

care was not rated blind to the presence or absence of dementia. However, evidence of care, decided a priori on the factors described in the methods section, was either written in the notes or absent. Dementia is under-diagnosed in patients admitted to the acute hospital sector, and some of those in our non-dementia group could well have been 'missed' cases. However, our intention was to investigate whether the perception that a patient has 'dementia' influences the end-of-life care that they receive.

Standard 2 of the English National Service Framework for Older People supports the use of better quality end-of-life care for older people, noting that 'many older people and their carers have also found that palliative care services have not been available to them' [24]. This study illustrates that patients who die with dementia in the acute hospital sector, have poor access to palliative care and that research in to service provision is urgently needed to remedy this situation.

Key points

- There is increasing awareness of the need to provide good quality palliative care to older people, but those with dementia have particular difficulty in accessing services.
- Older people, who died whilst admitted to acute hospital wards and who were documented in their medical notes as having dementia, received significantly fewer palliative medications or referrals to palliative care teams prior to death.
- In those patients where dementia was noted, there was less attention to spiritual needs and religious background.

ELIZABETH L. SAMPSON^{1,2*}, VIVIENNE GOULD³, DAN LEE⁴,
MARTIN R. BLANCHARD^{1,2}

¹Department of Mental Health Sciences, Royal Free & University
College Medical School, Rowland Hill Street,
London NW3 2PF, UK
Tel: (+44) 20 7794 0500x3708
Fax: (+44) 20 7830 2808
Email: e.sampson@medsch.ucl.ac.uk

²Camden and Islington Mental Health and Social Care Trust
St Pancras Hospital, St Pancras Way
London NW1 0PE, UK

³Barnet, Enfield and Haringey Mental Health Trust
Department of Psychiatry for Older People,
Chase Farm Hospital, The Ridgeway, Enfield,
Middlesex EN2 8JL, UK

⁴Royal Free Hospital Hampstead NHS Trust, Pond Street,
London NW3 2QG, UK

*To whom correspondence should be addressed

1. McCarthy M, Addington-Hall J, Altmann D. The experience of dying with dementia: a retrospective study. *Int J Geriatr Psychiatry* 1997; 12: 404–9.
2. Folstein MF, Folstein SE, McHugh PR. 'Mini-mental state'. A practical method for grading the cognitive state of patients for the clinician. *J Psychiatr Res* 1975; 12: 189–98.

3. Neale R, Brayne C, Johnson AL. Cognition and survival: an exploration in a large multicentre study of the population aged 65 years and over. *Int J Epidemiol* 2001; 30: 1383–8.
4. Morrison RS, Siu AL. Survival in end-stage dementia following acute illness. *JAMA* 2000; 284: 47–52.
5. House of Commons Health Committee. *Palliative Care. Fourth Report of Session 2003–04, Volume 1.* London: The Stationery Office, 2005.
6. Everett D. Forget me not: the spiritual care of people with Alzheimer's Disease. *J Health Care Chaplain* 1999; 8: 77–88.
7. Hodkinson HM. Evaluation of a mental test score for assessment of mental impairment in the elderly. *Age Ageing* 1972; 1: 233–8.
8. Morrison RS, Ahronheim JC, Morrison GR *et al.* Pain and discomfort associated with common hospital procedures and experiences. *J Pain Symptom Manage* 1998; 15: 91–101.
9. Ellershaw J, Ward C. Care of the dying patient: the last hours or days of life. *BMJ* 2003; 326: 30–4.
10. Molaschi M, Ponzetto M, Ferrario E, Scarafioti C, Fabris F. Health and functional status in elderly patients living in nursing homes. *Arch Gerontol Geriatr* 1995; 21: 267–76.
11. Olichney JM, Hofstetter CR, Galasko D, Thal LJ, Katzman R. Death certificate reporting of dementia and mortality in an Alzheimer's disease research center cohort. *J Am Geriatr Soc* 1995; 43: 890–3.
12. Maletta GJ. Access to hospice programs in end-stage dementia. *J Am Geriatr Soc* 1995; 43: 1174–5.
13. Ahronheim JC, Morrison RS, Morris J, Baskin S, Meier DE. Palliative care in advanced dementia: a randomized controlled trial and descriptive analysis. *J Palliat Med* 2000; 3: 265–73.
14. Hanrahan P, Luchins DJ. Feasible criteria for enrolling end-stage dementia patients in home hospice care. *Hosp J* 1995; 10: 47–54.
15. Baldereschi M, Di Carlo A, Maggi S *et al.* Dementia is a major predictor of death among the Italian elderly. ILSA Working Group. Italian Longitudinal Study on Aging. *Neurology* 1999; 52: 709–13.
16. Aevarsson O, Skoog I. A population-based study on the incidence of dementia disorders between 85 and 88 years of age. *J Am Geriatr Soc* 1996; 44: 1455–60.
17. Hughes JC, Robinson L, Volicer L. Specialist palliative care in dementia. *BMJ* 2005; 330: 57–8.
18. Sampson EL, Ritchie CW, Lai R, Blanchard MR, Raven PW. A systematic review of the scientific evidence for the efficacy of a palliative care approach in advanced dementia. *Int Psychogeriatr* 2005; 17: 31–40.
19. Morrison RS, Siu AL. A comparison of pain and its treatment in advanced dementia and cognitively intact patients with hip fracture. *J Pain Symptom Manage* 2000; 19: 240–8.
20. Marshall M. 'They should not really be here' – people with dementia in the acute sector. *Age Ageing* 1999; 28 (Suppl. 2): 9–11.
21. Laurila JV, Pitkala KH, Strandberg TE, Tilvis RS. Detection and documentation of dementia and delirium in acute geriatric wards. *Gen Hosp Psychiatr* 2004; 26: 31–5.
22. Mayou R, Hawton K, Feldman E, Ardern M. Psychiatric problems among medical admissions. *Int J Psychiatry Med* 1991; 21: 71–84.
23. Aminoff BZ, Adunsky A. Dying dementia patients: too much suffering, too little palliation. *Am J Alzheimers Dis Other Demen* 2004; 19: 243–7.
24. Department of Health. *National Service Framework for Older People*, London, 2001.

doi:10.1093/ageing/afj025

Published electronically 11 January 2006