A critical literature review exploring the challenges of delivering effective palliative care to older people with dementia

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Submitted for publication: 20 December 2006
Accepted for publication: 30 October 2007

Aim. This paper considers the challenges of delivering effective palliative care to older people with dementia and the possible strategies to overcome barriers to end-of-life care in these patients.

Background. In UK alone, approximately 100 000 people with dementia die each year and as the number of older people increases, dementia is set to become even more prevalent. Dementia is a progressive terminal illness for which there is currently no cure. Patients dying with dementia have significant health-care needs and in recent years it has been recognised that palliative care should be made available to everyone regardless of diagnosis, as this improves comfort and quality of life. Despite this, patients dying with dementia are often still not given access to palliative care services.

Method. A review of English language literature published after 1996 to the present day relating to older people with dementia during the terminal phase of their illness.

Results. Twenty-nine articles met inclusion criteria for the review. Most originated from North America and UK and were mostly quantitative in nature. Four key themes were identified: difficulties associated with diagnosing the terminal phase of the illness (prognostication); issues relating to communication; medical interventions; and the appropriateness of palliative care intervention.

Conclusions. This review reinforces the importance of providing appropriate palliative care to individuals suffering from end-stage dementia and identifies some of the barriers to extending such specialist palliative care provision.

Relevance to practice. There is an urgent need to improve palliative care provision for older people with end-stage dementia and, in addition, more research is required on the needs of patients entering the terminal phase of dementia to assist the allocation of appropriate resources and training to ensure quality and equality in the provision of end-of-life care.

Key words: dementia, end-of-life, nurses, nursing, palliative care, systematic review
Introduction

Demographic trends show that older people living in UK will increase in number over the next 20 years (Office for National Statistics 2005), with a particular marked rise in the group aged 85 years and over. Overall, life expectancy is increasing throughout Europe with more and more people living beyond the age of 65 years (Davies & Higginson 2004, Payne & Froggatt 2006). In UK alone, 83.5% of deaths are people over the age of 65 (CancerStats 2005) and yet these people are less likely than younger people to have access to health and social services (Seymour et al. 2005).

The incidence of dementia increases from one in 1000 in those below the age of 65 years to one in five in those over the age of 85 and is set to become even more prevalent (Luchins et al. 2003) and the Liverpool Care Pathway (LCP) (Ellershaw & Wilkinson 2003). Although the term ‘palliative care’ was originally applied primarily provided for patients with terminal cancer. Although the term ‘palliative care’ was originally applied only to the terminally ill, it has now been broadened to include those who have a life-threatening illness not amenable to curative treatment and who are not necessarily imminently dying and may thus have a prognosis of months to years (National Council for Palliative Care 2007). However, there is increasing evidence that these patients with diseases other than cancer have difficulty accessing specialist palliative care services (National Council for Palliative Care 2007). Given the increasing prevalence of people dying with dementia, palliative care for these older people is extremely relevant (Roger 2006). The purpose of this paper, therefore, is to explore the evidence relating to end-of-life care for older people with dementia.

Search strategy

ASSIA, PsychInfo, CINAHL, MEDLINE, EMBASE, BNID and AMED databases were searched, using the keywords palliative care, end-of-life and dementia. The reference lists of located papers were also searched for relevant articles. The search was further amplified by hand searches of what was considered the most relevant and accessible journals: Palliative Care Today, Palliative Medicine and Nursing Older People.

Inclusion criteria were papers relating to older people with dementia, end-of-life or palliative care, published after 1996 in the English language. From a possible 118 articles identified, 29 met the inclusion criteria and were included in the review (Table 1).

Findings and discussion

Twelve papers originated in the USA, eight in the UK and the remainder coming from Canada (n = 2), Israel (n = 2), Switzerland (n = 1), Ireland (n = 1), Netherlands (n = 1), Sweden (n = 1) and Finland (n = 1). Twenty studies were quantitative (either surveys or randomised controlled trials), two qualitative, four literature reviews and two theoretical papers. Several recurrent themes were identified and are now discussed.

Prognostication

Prognosis

Realistic prognoses are essential to allow patients and their carers to prepare realistic expectations for the short- to medium-term course of the disease. However, prognostic uncertainties seen in all serious illness are amplified in patients suffering from advanced dementia (Sampson et al. 2006a). Carpenter (2004) suggests that one of the challenges in the management of patients with dementia is that cognitive
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<tr>
<td>Michel et al. (2002), Switzerland, Review</td>
<td>Review of the literature on end-of-life care of persons with dementia</td>
<td>Search strategy and inclusion exclusion criteria not detailed</td>
<td>Not detailed</td>
<td>Not applicable</td>
<td>Not applicable</td>
<td>Dementia is a risk factor for early death &lt;br&gt;No survival differences between Alzheimer’s and Lewy body disease, although patients with vascular dementia have the worst prognosis &lt;br&gt;Cardiac causes of death are significantly more frequent in vascular dementia than other types &lt;br&gt;Ethical issues not close consideration &lt;br&gt;Need for improvement in communication with both patients and carers</td>
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<tr>
<td>Sampson et al. (2006b), England, Retrospective case note study</td>
<td>To compare difference of care received by patients with and without dementia, who died during acute hospital admission</td>
<td>Aged 70 years and over &lt;br&gt;Patients who died whilst inpatient on an acute hospital ward between 1 April 2002 and 31 March 2003 &lt;br&gt;Notes selected using random number tables</td>
<td>Data extracted from medical notes</td>
<td>Demographic information including age, gender, type &amp; severity of dementia and religious faith &lt;br&gt;Abbreviated Mental Test Scores (AMTS) &lt;br&gt;Mini Mental State Examination (MMSE) &lt;br&gt;End of life care assessed using Liverpool Care Pathway Statistical analysis performed using <strong>SPSS</strong> (version 11.0) &lt;br&gt;Relationship between dementia status &amp; dichotomous variables investigated using Fisher’s exact test &lt;br&gt;Mann-Whitney U-test was used for continuous variables</td>
<td>Ethical approval obtained via hospital ethics committee</td>
<td>Dementia patients have particular difficulty assessing palliative-care services &lt;br&gt;Older people with dementia receive significantly fewer palliative care medications &lt;br&gt;Dementia patients have less attention paid to the identification of spiritual needs and religious background</td>
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<tr>
<td>Lloyd-Williams and Payne (2002), England, Retrospective audit</td>
<td>To see if multidisciplinary guidelines improve the palliation of symptoms in the terminal phase of dementia</td>
<td>All deaths over 12-month period in a long stay psychiatric hospital Dates not provided</td>
<td>Data extracted from medication cards and case notes.</td>
<td>Demographic information 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 route of administration used</td>
<td>Not identified</td>
<td>Multidisciplinary guidelines can improve palliative care.</td>
</tr>
<tr>
<td>Aminoff and Adunsky (2004), Israel, Quantitative</td>
<td>To evaluate the level of suffering of end-stage dementia patients during their final hospital stay using the MSSE tool (Mini Suffering State Examination)</td>
<td>Studied consecutive end-stage dementia patients over 2-year period Diagnosis based upon the DSM-4 revised criteria for dementia Patients eligible if suffering severe dementia interfering with verbal communication. Dependent for Activities of Daily Living and functional movement</td>
<td>Level of suffering was evaluated weekly from admission by the MSSE by medical staff and the patients family</td>
<td>Demographic and clinical variables analysis of variance (ANOVA) Kruskal-Wallis non-parametric test Fisher’s exact test Statistical significance level was set to 0.05 SPSS used for data analysis Limitations of study identified form differences regarding the definition and nature of suffering</td>
<td>Authorised by local ethics Helsinki Committee</td>
<td>Most end-stage dementia patients (63%) die with a high level of suffering Despite traditional treatment efforts to ease, the patients condition by staff, the medical community fails to minimise the suffering of persons dying with advanced dementia The MSSE scale can be sued to monitor the extent of suffering Routine use of the MSSE would improve awareness and facilitate treatment strategies aimed at diminishing the level of suffering at end-stage dementia patients.</td>
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<td>Study</td>
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<td>Ahronheim et al. (1996), USA, Quantitative</td>
<td>To compare the treatment and diagnostic interventions given to two groups of incurably ill, elderly patients in their last days of life: patients with advanced cancer and those with advanced dementia.</td>
<td>All patients 65 years and older who died with a diagnosis of advanced dementia or metastatic cancer at a large New York teaching hospital for 13 months between 1992 and 1993.</td>
<td>Immediate cause of death was obtained from the patient’s death certificate.</td>
<td>Incurably ill patients often receive non-palliative interventions at the end of life. Patients with cancer receive more diagnostic tests, but patients with dementia receive more enteral tube feeding.</td>
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<tr>
<td>Ahronheim et al. (2000), USA, randomised controlled trial and descriptive analysis, Quantitative</td>
<td>To determine if a palliative care approach could be implemented for patients with advanced dementia and if this approach could enhance patient comfort.</td>
<td>Ethical approval obtained.</td>
<td>Study failed to demonstrate that a palliative care intervention by a team could have an impact on specific treatment plans in hospitalised patients with advanced dementia. There may be unique barriers including perceived prognostic uncertainty, difficulty assessing comfort levels and perceptions about tube feeding. Further study to identify patients prior to the need for acute hospitalisation so goals can be established when there is less urgency to make life and death decisions.</td>
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<td>Evers et al. (2002), USA, Quantitative</td>
<td>To establish the frequency of palliative and aggressive treatment measures among patients with and without dementia during the last six months of life</td>
<td>All patients lived in chronic care facilities at time of death</td>
<td>Post-mortem chart review Antemortem data for 279 patients with dementia and 24 control patients Between 1985 and 2000 this was then divided into three cohorts</td>
<td>Severity of dementia was defined by clinical dementia rating scale Chi-squared test were used to compare categorical variables</td>
<td>Ethics approval obtained</td>
<td>Systematic antibiotics are prevalent in the treatment of patients with end-stage dementia, despite the limited utility and discomfort associated with the use of these agents. Patients with dementia were significantly less likely to have received narcotic pain medication. Findings confirm the aggressive nature of treatment of persons with dementia that have been reported in other studies. Although pain management may be improving, the practice of using antibiotics does not appear to have changed.</td>
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<tr>
<td>Maguire et al. (1996), Ireland, Survey</td>
<td>To report the results of a survey of family members on their attitudes to disclosure of diagnosis of Alzheimer’s disease</td>
<td>100 consecutive family members accompanying patients with diagnosed Alzheimer’s disease</td>
<td>Survey of three questions: 1. Should patient be told their diagnosis? 2. Would relatives want to be told their diagnosis if it was them 3. Would they make use of a predictive test for Alzheimer’s should it become available?</td>
<td>Not identified</td>
<td>Not identified</td>
<td>83% said that patient should not be told there diagnosis 71% said they would want to be told if it was them 75% would like to use a predictive test if available.</td>
</tr>
<tr>
<td>Hinkka et al. (2002), Finland, Quantitative</td>
<td>To study the association of personal background factors with end-of-life decisions among Finnish doctors comparing to scenarios involving a terminally ill cancer patient and a dementia patient</td>
<td>Questionnaire sent to: 300 surgeons 300 internists 82 GPs</td>
<td>Postal survey 1999</td>
<td>Likert-type scale analysis Statistical significance was tested with Pearson’s chi-square test Student’s t-test One way analysis of variance (ANOVA) SPSS</td>
<td>Not identified</td>
<td>Doctors’ end-of-life decisions vary widely according to personal background factors. The findings underline the importance of advance communication, making these decisions in accordance with the patient’s wishes.</td>
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<td>Volicer et al. (2003), Retrospectivesurvey, Quantitative</td>
<td>To describe the characteristics of end-of-life care in different settings and to develop three scales designed specifically to measure end-of-life care outcomes in dementia</td>
<td>Retrospective survey of a nationwide sample of family caregivers of demented individuals who died during the year preceding the survey</td>
<td>Questionnaire 938 distributed questionnaires but only 27% response rate</td>
<td>ADL's measured by the six-item Katz Index of Activities of Daily Living</td>
<td>Fisher's least significant difference tests</td>
<td>Ethics approval obtained</td>
</tr>
<tr>
<td>Campbell and Guzman (2004), USA, Quantitative</td>
<td>To compare usual care with a proactive case-finding approach for critically ill patients with terminal dementia using an inpatient palliative care service</td>
<td>Retrospective chart review Patients with advanced-stage dementia admitted to ICU</td>
<td>26 patients included from 1999 to 2001</td>
<td>Dementia severity measured by the Bedford Alzheimer Nursing Scale Caregiver burden was measured by the Caregiver Burden Inventory ANOVA Fisher's least significant difference tests</td>
<td>ANOVA Ethical approval granted</td>
<td>A proactive palliative intervention decreased the time between identification of the poor prognosis and the establishment of DNAR goals, decreased time terminal demented patients remain in ICU Reduction in the use of non-beneficial resources Physicians are more comfortable with not adding life support and resuscitation but less confident about stopping interventions, symptom management and family grief support Pain and dyspnoea were the most common symptoms There is a need for education of both nursing and medical staff regarding principles of palliative care</td>
</tr>
<tr>
<td>Lloyd-Williams (1996), England, Audit</td>
<td>To determine the most prevalent symptoms in terminal dementia and to assess the palliation given</td>
<td>Case notes of most recent 25 patients deaths with end stage dementia</td>
<td>Death certificate should contain dementia as a contributory cause of death Main symptoms recorded</td>
<td>Not identified</td>
<td>Not identified</td>
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<tr>
<td>Volicer <em>et al.</em> (2001), USA, Questionnaire, Quantitative</td>
<td>To study three scales designed to measure outcomes of care of persons suffering from terminal dementia</td>
<td>Questionnaire of family caregivers whose loved one died during the previous year Response rate only 27.3%</td>
<td>Via Questionnaire</td>
<td>Katz Index of ADL Dementia Severity – Bedford Alzheimer Nursing Scale Distribution of values in each scale was compared with normal distribution by calculating skewness and kurtosis</td>
<td>Ethical approval granted</td>
<td>The three scales developed and evaluated in this study can be used as outcome measures in studies investigating effectiveness of interventions aimed to improve end-of-life care for individuals with dementia</td>
</tr>
<tr>
<td>McCarthy <em>et al.</em> (1997), England, Quantitative</td>
<td>To describe the last year of life of people with dementia, the symptoms, care needs, use of and satisfaction with health services and the bereavement state of respondents</td>
<td>A retrospective sample survey of the carers, family members or others who knew about the last year of life 170 patients with dementia were identified compared with 1513 cancer patients</td>
<td>Interviews 10 months after death of patient</td>
<td>Chi-square test was used to compare frequencies</td>
<td>Not identified</td>
<td>Most common symptoms: mental confusion (83%), urinary incontinence (72%), pain (64%), low mood (61%), constipation (59%), loss of appetite (57%) Dementia patients saw their GP less often than cancer patients and rated GP assistance less highly Dementia patients needed more help compared to cancer patients at home</td>
</tr>
<tr>
<td>Keene <em>et al.</em> (2001), England, Quantitative</td>
<td>To investigate the last phase of dementia and the causes of death, comparing autopsy and death certificate</td>
<td>11-year, longitudinal study of participants with dementia living at home with a carer All lived in Oxfordshire, UK</td>
<td>Comparison of autopsy and death certificates diagnosis</td>
<td>Present Behaviour Examination (PBE) Mini Mental State Examination (MMSE)</td>
<td>Ethics approval granted</td>
<td>Immediate care of death = pneumonia (57%) cardiovascular disease (16%), pulmonary embolus (14%) Dementing illness lasted a mean of 8.5 years Death certificates frequently provide inadequate or incorrect information about cause of death</td>
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<td>Study</td>
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<tr>
<td>Morrison and Siu (2000), USA, Quantitative</td>
<td>To examine survival for patients with end-stage dementia following hospitalisation for hip fracture or pneumonia and to compare their care with that of cognitively intact older adults</td>
<td>Patients 70 years and older hospitalised with hip fractures or pneumonia who had a diagnosis of dementia in a large New York hospital between 1996 and 1998</td>
<td>Hospital chart evaluation, X2 Analyses and t-tests were used to compare patient characteristics and other variables</td>
<td>The Cox proportional hazards regression model was used to examine survival</td>
<td>High 6-month mortality for patients with end-stage dementia following hospitalisation for pneumonia (53%) or hip fracture (55%)</td>
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<tr>
<td>Roger (2006), Canada, Review</td>
<td>Review of the literature on palliative care of those dying with dementia</td>
<td>Search strategy</td>
<td>NA</td>
<td>NA</td>
<td>NA</td>
<td>Primary themes discussed are person-centred approaches, grief, agitation, aggression, pain management, care provision, training and education, decision-making, primary settings of care and spirituality and dignity. Gaps in the literature are identified</td>
</tr>
<tr>
<td>Engel et al. (2006), USA, Cross-sectional study</td>
<td>To identify factors associated with satisfaction with care for healthcare proxies of nursing home residents</td>
<td>13 nursing homes in Boston 148 residents aged 65 and over with advanced dementia and their formally designated healthcare proxies</td>
<td>Satisfaction with care at the end-of-life scale, Descriptive and inferential statistics</td>
<td>Ethical approval obtained</td>
<td>Variables independently associated with greater satisfaction were discussed re-advanced directives, greater resident comfort, care in a specialised dementia unit and no tube feeding</td>
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<tr>
<td>Downs et al. (2006), UK, Theoretical paper</td>
<td>To discuss four models used to understand dementia: Neurological, neuropsychiatric, normal ageing and person-centred approaches.</td>
<td>NA</td>
<td>NA</td>
<td>NA</td>
<td>NA</td>
<td>Adopting a person-centred approach ‘has the potential to enrich the end-of-life experience of people with dementia, of their families and of the professional care staff who work with them. They call for the development of “imaginative care practices”'</td>
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<tr>
<td>Sampson et al. (2006a), UK, Systematic review</td>
<td>To complete systematic review regarding the efficacy of a palliative care model for patients with dementia</td>
<td>Structured literature search using a full range of databases</td>
<td>30 articles identified, four eligible for full appraisal but only two met full criteria for inclusion</td>
<td>NA</td>
<td>Ethical issues concerning the ability to conduct ethically robust research studies</td>
<td>Only equivocal evidence of the efficacy of a palliative care approach. This may be due to ethical challenges of doing research in this area, issues to do with prognostication and communication difficulties for patients with advanced dementia.</td>
</tr>
<tr>
<td>Mitchell et al. (2004a), USA, Retrospective cohort study</td>
<td>To describe and compare the end-of-life experiences of older people dying from advanced dementia in nursing home and home care settings</td>
<td>People over 65 who had died within 1 year of admission to nursing home (n = 2730) and home care settings (n = 290)</td>
<td>Minimum Data Set data used</td>
<td>NA</td>
<td>NA</td>
<td>5.7% nursing home residents referred to hospice compared with 10.7% of home care residents. Hospitalisations were frequent, pain and shortness of breath were common in both settings. ‘Persons dying with advanced dementia admitted to nursing homes have different characteristics compared to those admitted to home care services. Their end-of-life experiences also differ’</td>
</tr>
<tr>
<td>Sachs et al. (2004), USA, Theoretical paper</td>
<td>To discuss the challenges to providing high quality end-of-life care for patients with dementia</td>
<td>NA</td>
<td>NA</td>
<td>NA</td>
<td>Discussed in the context of promoting high quality care</td>
<td>They comment on the way in which dementia is still not considered by some as a terminal illness; decision making in advanced dementia treatments; symptom assessment and management; experiences of the caregiver; bereavement</td>
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### Table 1 (Continued)

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<tr>
<td>Aminoff and Adunsky (2006)</td>
<td>Israel, Cohort study</td>
<td>To study any relationship between Mini-Suffering State Examination (MSSE) scale and survival of end-stage dementia patients</td>
<td>Cohort study of 252 end-stage dementia patients with a 6-month follow-up</td>
<td>MSSE scores</td>
<td>Descriptive and inferential statistics</td>
<td>Approval obtained</td>
</tr>
<tr>
<td>Mitchell et al. (2004b), USA, Retrospective cohort study</td>
<td>To compare the end-of-life experiences of patients with advanced dementia and terminal cancer admitted to nursing homes in New York</td>
<td>People over 65 years with advanced dementia (n = 1609) and terminal cancer (n = 883) who died within a year of admission to nursing homes in New York</td>
<td>Minimum data set</td>
<td>Descriptive and inferential statistics</td>
<td>Only 1-1% of dementia patients considered to have life expectancy of less than 6 months (71% died in that period). Non-palliative interventions were common amongst these patients. These patients were also less likely than those with cancer to have advanced directives. They conclude that dementia is not considered as a terminal illness and call for educational and management strategies.</td>
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<tr>
<td>Forbes et al. (2000), USA, Focus group study</td>
<td>To examine the affective and cognitive decision making processes regarding end-of-life treatments for nursing home residents</td>
<td>Family members (n = 28) participated (aged 41–85 years)</td>
<td>Focus groups</td>
<td>Thematic qualitative data analysis</td>
<td>Five themes generated: emotional effect; insult-to-life story; two faces of death; values and goals regarding end-of-life treatment; and the unrecognised dying trajectory. They concluded that family members need support during this process</td>
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<td>Robinson et al. (2006), UK, Review</td>
<td>To review current knowledge around end-of-life care in dementia</td>
<td>NA</td>
<td>NA</td>
<td>NA</td>
<td>NA</td>
<td>Evidence of the effectiveness of a specialist hospice service for people with dementia is limited. They suggest that continuing care beds could provide potential. They conclude that much needs to be done to improve the care provided to people dying in the end stages of dementia</td>
</tr>
<tr>
<td>Rurup et al. (2006), Netherlands, Survey</td>
<td>To investigate the attitudes of physicians, nurses and relatives towards medical end-of-life decisions concerning patients with dementia</td>
<td>Physicians, nurses, relatives</td>
<td>15 statements about artificial feeding and hydration, advanced directives, hastening death, self-determination and euthanasia presented to the sample</td>
<td>Thematic analysis</td>
<td>There was much agreement on many of the issues. However, relatives attached more importance to AD than physicians and are more amenable to strategies hastening death</td>
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<tr>
<td>Albinsson &amp; Strang 2002, Sweden Phenomenological interview study</td>
<td>To investigate how staff caring for patients with dementia deal with life and death (existential) issues</td>
<td>31 carers, mostly unqualified nursing staff</td>
<td>Qualitative interviews</td>
<td>Phenomenological approach taken to analysis</td>
<td>Approval granted by regional ethics committee</td>
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<tr>
<td>Caron et al. (2005), Canada, Grounded theory qualitative study</td>
<td>To explore the experience of family care givers in making end-of-life decisions</td>
<td>24 care givers involved in the care decisions of an older family member with advanced dementia</td>
<td>Interviews</td>
<td>Constant comparative data analysis method</td>
<td>Ethical approval granted</td>
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</table>

All participants found existential issues difficult to discuss with both patients and their family members. They make recommendations for improving end-of-life care.

They identified five dimensions associated with decision making at the end of life: dimensions associated with the person with dementia; dimensions associated with the caregiver; treatment; family context; and context of interactions with health-care providers. They recommend that care standards are needed to guarantee family participation in dementia care.
impairment may hinder treatment because of limited ability to either consent and/or adhere to treatment. For example, at the extreme of refusal to consent, the patient may not take sufficient food and fluids to maintain their health. In addition, the persistent inability to eat when fed may also be a marker of the terminal stage of the disease (Ahronheim et al. 1996, Volicer 2001).

Another potential indicator is identified by Morrison and Siu (2002). In a prospective cohort study in USA, they examined the survival of patients with end-stage dementia by monitoring 216 patients over six months and found a high mortality in patients following hospitalisation for pneumonia (53%) or hip fracture (55%) compared with cognitively intact patients. But despite these findings they found almost no differences in the care these patients received compared with cognitively intact adults, and no evidence that palliative care was undertaken either in conjunction with or instead of life-prolonging measures for dementia patients. Despite the limitations to the study which preclude wider generalisation, the data suggest that advanced dementia is not viewed as a terminal diagnosis by physicians or families. Morrison and Siu (2002) suggest this may be because physicians and families may not always be aware of the poor short-term prognosis for these patients.

In a systematic review, Coventry et al. (2005) identified three further studies to determine prognosis in hospice-based patients with dementia. In the studies attempting to assess survival in dementia patients, the weight of evidence presented was generally poor. Sample sizes were small and disease progression was not clear (Hanrahan & Luchins 1995, Luchins et al. 1997, Hanrahan et al. 1999). Coventry et al. (2005) reported finding no prognostic model which could be recommended for routine clinical use without further validation. However, in the context of identifying those patients likely to benefit from palliative care services, Aminoff and Adunsky (2006) concluded in their cohort study of patients with dementia (n = 252), that use of the Mini-Suffering State Examination Scale helped to identify those end-stage dementia patients most likely to benefit from palliative care provision.

Prognostication is a complex and challenging task that relies primarily on clinical judgement (Von Genten & Twaddle 1996, Coventry et al. 2005). In most non-cancers, dementia being a prime example, the difficulty is in the ‘entry re-entry’ death trajectories that these illnesses present (Murray et al. 2005). Indeed, Albinsson and Strang (2002, p. 169) suggest that ‘the fact that dementia is not seen as a palliative illness is probably because of the long period of time that often elapses between detection of the illness and death.’

Figure 1 Frailty and dementia trajectory – diagnosis to death

Three distinct illness trajectories have been described for people with progressive chronic illnesses: a trajectory with steady progression and usually a clear terminal phase, mostly cancer; a trajectory (for example respiratory or heart failure) with gradual decline, punctuated by episodes of acute deterioration and some recovery, with more sudden, seemingly unexpected deaths; and a trajectory with prolonged gradual decline typical of frail older people or people with dementia (Fig. 1) (Murray et al. 2005). Stewart and McMurray (2002) go so far as to describe it as ‘prognostic paralysis’, whereby clinicians of patients with uncertain illness trajectories prevaricate when considering end-of-life issues. This may be in part due to physicians’ often inaccuracy in predicting time-frames. However, few studies exist on the accuracy of physician prognostication. Where it has been evaluated, physicians are generally overly optimistic when predicting mortality, in some cases up to five times so (Christakis & Lamont 2000). Inaccurate reporting and doctors’ personal values and beliefs may be explanations for the accuracy of physician prognostication.

Doctors’ own values/beliefs
In a Finnish study, Hinkka et al. (2002) examined the personal background of doctors and investigated whether there was a relationship between this and decisions made regarding end-of-life. Their postal questionnaire (n > 1000, response rate 62%) indicated that Finnish physicians have different views on and approaches to, what they consider to be end-of-life. Their questions (n = 1000, response rate 62%) indicated that Finnish physicians have different views on and approaches to, what they consider to be end-of-life. If the doctor is young, female, single and has no experience of severe illness in her family, she is much more likely to make a decision in favour of active treatment (Hinkka et al. 2002). They also tended to be influenced to a greater extent by fears of legal consequences in the case of complications.
Ethical considerations

Palliative care aimed at older people frequently raises ethical issues about the boundaries between curative, palliative and useless care (Wary 2003). Most physicians feel guilty about issues relating to the death of patients and there is also much uncertainty about the legal implications of end-of-life decisions. Consequently, they tend to focus on the acute, potentially reversible illnesses that prompted hospitalisation which permits avoidance of the terminal context of the patient’s acute exacerbation (Hinkka et al. 2002, Campbell & Guzman 2004). The decision to withdraw or withhold is much more difficult than the decision to commence or continue treatment (Hinkka et al. 2002).

While there remains uncertainty about prognosis, there is a real fear that patients with dementia and their families will be neglected from appropriate health and social services (Murray et al. 2005). Furthermore, Coventry et al. (2005) argue that the main barrier to extending specialist palliative care services to older, non-cancer patients relates to clinicians’ reluctance and/or inability to predict palliative status and time-to-death. However, a protracted dying process is costly and older people are increasing in numbers continuously (Von Genten & Twaddle 1996, Evers et al. 2002, Aminoff & Adunsky 2004). Wary (2003) suggests that there is a risk of a drift towards ‘economic euthanasia’ – a reluctance to identify people with protracted dying processes to prevent further demand on palliative care services – unless the problem is acknowledged and an ethically acceptable solution found.

Multi-disciplinary teams

Quality care at end-of-life is highly individual and should be achieved through a process of shared decision-making and clear communication that acknowledges the values and preferences of patients and their families (Steinhauser et al. 2000). One way of achieving this is through the effective use of multi-disciplinary teams (MDT) and guidelines.

Lloyd-Williams and Payne (2002) conducted a retrospective audit to determine whether the use of MDT guidelines, which included reference to the importance of effective communication, would improve the palliation of symptoms in the terminal phase of dementia. They extracted data from notes of patients who had died over 12 months (n = 27) in a long-stay psychiatric hospital and identified a range of symptoms such as pain, dyspnoea and pyrexia. Guidelines were then developed to manage these symptoms. Results of a repeat audit indicated that the MDT was able to use the guidelines to improve palliation of symptoms. However, as this was a very small-scale study, transferability to other acute settings is limited. Nevertheless, Seymour et al. (2001) also support the value of a MDT approach as a way to emphasise quality of life as a key determinant of choices in care and treatment options.

Communication of diagnosis

Advances in the accuracy of the diagnosis of dementia (Hedera 2001) have initiated debate on whether patients should be informed of their diagnosis. For example, Addington-Hall et al. (1998) suggest more work is needed to explore how much information about their prognosis ‘non-cancer’ patients in general would like to be given and to investigate the practicalities of providing this information, given the difficulties of estimating prognosis in non-malignant disease. While acknowledging the particular challenges of assessing the needs of patients with dementia, it is perhaps reasonable to assume that this group of patients would not be any different to other ‘non-cancer’ patients with respect to prognosis disclosure. Sensitive communication of the diagnosis is beneficial as patients may be able to participate in decisions regarding their future healthcare before their condition deteriorates and they are rendered incapable of making such decisions themselves.

In a survey of family members of patients with dementia conducted in Ireland, Maguire et al. (1996) found that 83% of relatives said that patients should not be told their diagnosis. In contrast, however, 71% of them felt that if it was them then they would want to be told. Most of those who opposed disclosure felt that it could precipitate symptoms of anxiety and depression. However, Meyers (1997) argued that there is no empirical evidence to indicate that

Communication

Barriers to effective communication about end-of-life issues are well recognised (Murray et al. 2005) and in the context of older people with dementia these can be further challenged. An important caveat in devising palliative care recommendations for patients with advanced dementia is that it is not always possible to know with any certainty what the patients themselves want (Ahronheim et al. 1996). Furthermore, when older people become unable to make decisions themselves, family members are called upon to do so. Caron et al. (2005), in a grounded theory study of 24 family care givers in Canada, concluded that working in partnership with families is crucial and that ‘communication of information is the utmost need expressed by family care givers’ (Caron et al. 2005, p. 244). Therefore, professionals, carers and where at all possible the patients themselves, need to work together to plan the most appropriate care required to meet the individual needs of each patient (Engel et al. 2006).
awareness of diagnosis causes stigmatisation and depression and suggests it has substantive benefits. But ultimately as Meyers (1997) concludes, the risks and benefits of having diagnostic information will vary according to the severity of the dementia.

Advanced directives
Advanced directives are a relatively recent introduction within UK, originating predominantly from USA, where much of the limited research on end-stage dementia has been done. One of the key issues with dementia is that unless communication is initiated in the early stages of the disease, loss of cognitive function makes taking individual’s views into consideration difficult, if not impossible, which in turn increases the emotional burden on carers.

In a cross-sectional study of nursing home residents in USA, Engel et al. (2006) found that time devoted to discussing advanced directives was associated with greater satisfaction with care for people with advanced dementia. In addition to formal advanced directives, there is also some evidence that advance care planning in general may help to address not only the needs of patients but those of family members. In their study of the attitude of physicians, nurses and relatives towards medical end-of-life decisions, Rurup et al. (2006) found that relatives attached more importance to advanced directives than physicians and concluded that end-of-life decisions should be communicated more openly.

Currently, however, a conversation with patients and families about advanced care planning appears to occur late, if at all (Mast et al. 2004). Hinkka et al. (2004) argue that advanced communication among patients, families and physicians facilitates informed decision-making on the basis of the patient’s preference rather than on the basis of physicians’ attitudes and values.


Medical interventions
There is significant evidence of older people with end-stage dementia having poor pain control (Mitchell et al. 2005, Sachs et al. 2004), feeding tubes inserted (Sachs et al. 2004) and inappropriate treatments such as restraints and laboratory tests (Mitchell et al. 2004a). There is much debate, therefore, concerning the appropriateness of medical interventions for dementia patients, with substantial evidence that an aggressive medical approach is of limited efficacy (Ahronheim et al. 1996, Lloyd-Williams 1996, Morrison & Siu 2000, Volicer 2001, Evers et al. 2002, Hinkka et al. 2002, Sampson et al. 2006b). End-stage dementia has been associated with a poor prognosis and a limited life expectancy, which are not improved by invasive procedures (Morrison & Siu 2000, Evers et al. 2002).

Sampson et al. (2006b) conducted a retrospective case-note audit of older patients dying on an acute medical ward in a London hospital in 2002/2003 (n = 35 with dementia and n = 65 without). With respect to medical management, there was some evidence that invasive procedures were limited in patients with dementia, for example central line insertion (3% with dementia vs. 20% without). However, significantly more patients were documented as having measurement of blood gases (80 vs. 58%; p = 0.024) and insertion of urinary catheters (77 vs. 57%; p = 0.035) and nasogastric tubes (40 vs. 23%; p = 0.062). Referral to palliative care teams and the prescription of palliative medications was significantly less frequent, however, in patients documented as having dementia (8 vs. 25%) suggesting that dementia appears not to be viewed as a ‘terminal’ disease (Sampson et al. 2006b).

In Hinkka et al.’s (2002) study, active treatment was chosen more often for the critically ill dementia patient than for the cancer patient in their scenarios presented to doctors, reinforcing Sampson et al’s (2006b) argument. Knowing that we cannot cure or arrest the progression of most dementias, palliative care or providing comfort and good quality-of-life for individuals with this diagnosis should be therefore the treatment priority (Head 2003).

Evers et al. (2002), in a quantitative study conducted in USA, examined the frequency of palliative and aggressive treatments delivered during the previous six months of patients’ life with and without dementia. They found that use of systemic antibiotics was prevalent in the treatment of patients with end-stage dementia (53%), despite the limited utility and associated discomfort (Morrison & Siu 2000). Evers et al. (2002) suggest that possible reasons for the high prevalence of antibiotic treatment include a lack of advance directives, inadequate training of physicians in discussing end-of-life decisions and prognostic uncertainty about the course of the disease. These findings confirm the aggressive nature of treatment of dementia sufferers reported in other studies (Fabiszewski et al. 1990).

In another North American study, Ahronheim et al. (1996) compared charts of 164 patients (80 with dementia and 84 with cancer) and identified again that incurably ill patients often received non-palliative interventions at the end of life.
However, in contrast to Sampson et al. (2006b) and Hinkka et al. (2004), patients with cancer actually received more diagnostic tests and patients with dementia received more enteral tube feeding. However, in their study to identify the factors promoting satisfaction with the care of older people with advanced dementia, Engel et al. (2006) found that ‘no tube feeding’ was associated with increased satisfaction with care.

**Symptom control**

Several studies have emphasised the need for implementing good palliative care for patients with dementia and that palliation of symptoms leads to improved comfort and quality of life (Ryan 1989, Fabiszewski et al. 1990, Luchins & Hanrahan 1993, Hanrahan & Luchins 1995). In a small case-note audit of 25 patients with dementia whose notes were reviewed retrospectively after death, Lloyd-Williams (1996) found that patients had symptoms during the terminal phase of their illness which were amenable to palliation. But, in all cases palliation was either inadequate or non-existent. The most frequently reported symptoms were dyspnoea, pyrexia and pain.

In a larger comparative quantitative study of patients with dementia \((n = 170)\) and cancer \((n = 1513)\), McCarthy et al. (1997) found that the most frequent symptoms reported for dementia patients in the last year of life were: mental confusion (83%), urinary incontinence (72%), pain (64%), low mood (61%), constipation (59%) and loss of appetite (57%). Although the number of reported symptoms dementia and cancer patients experienced was similar, there were differences between the two groups with respect to the frequency of the symptoms, with dementia patients experiencing symptoms for longer (McCarthy et al. 1997). The futility and discomfort of aggressive treatments, combined with the under-recognition and under-treatment of pain and other symptoms among patients with severe dementia, further supports the use of palliative care approaches for this patient group (Evers et al. 2002).

**Palliative care implications**

Palliative care is based on the concept of reinforcing factors that improve quality of life and decreasing those that reduce quality (Hallberg 2006). It is now widely accepted that the principles of palliative care are applicable to patients with non-malignant disease (Lloyd-Williams & Payne 2002, Sachs et al. 2004). However, there is significant evidence that older people dying from dementia ‘are not perceived as having a terminal condition and most do not receive optimal palliative care’ (Mitchell et al. 2004, p. 321). They represent what Robinson et al. (2006) call the ‘disadvantaged dying’ (p. 135).

In a randomised controlled trial conducted in America, Ahronheim et al. (2000) monitored eligible patients over three years \((n = 48\) intervention group, \(n = 51\) control group) to determine if a palliative care approach could be implemented for patients with advanced dementia. Results failed to demonstrate that palliative care interventions by a specialist team could have an impact on specific treatment plans. The study highlighted the importance of advanced planning for palliative care in care settings other than the acute sector and recommended that there should be attempts to identify patients prior to the need for acute hospitalisation, whereby goals could be established when there was less urgency to make life and death decisions. There were, however, several limitations to this study including small patient numbers and the possibility of a Type II error.

In contrast, another American study (Campbell & Guzman 2004) investigated whether a palliative care approach was beneficial for critically ill patients with terminal dementia admitted to an Intensive Care Unit (ICU). They concluded that proactive palliative intervention decreased the time between identification of the poor prognosis and the establishment of ‘Do not Attempt Resuscitation’ (DNAR) goals.

Despite the contradictory findings of Ahronheim et al. (2000), the general consensus is that palliative care is appropriate for patients who are considered to be in the terminal stage of their illness (Absolon 1998, Cox & Keady 1999, Albinsson & Strang 2002, Lloyd-Williams & Payne 2002, Wary 2003).

**Place of care**

Volicer et al. (2003) conducted a retrospective nationwide survey across USA of families whose relatives had died within a 12-month period, to consider the characteristics of care in different settings for patients with terminal dementia. They found that the end-of-life experience of individuals with dementia differed according to care settings. They concluded that if the person was cared for at home during the last 90 days they experienced fewer symptoms than those cared for in other areas. However, they did acknowledge that the difference in symptom occurrences across the various settings could have been due to either different treatment strategies or differences in characteristics of the individual. It should however be noted that the study achieved a response rate of only 27-3%.

In another study comparing place of death, Mitchell et al. (2004a,b) conducted a retrospective cohort study in USA of older people with dementia dying in either nursing home or home-care settings. They found that only 5–7% of those
residents in nursing homes were referred to a hospice, compared with 10.7% of those resident in home-care settings. Nursing home residents were more likely to be admitted to hospital (43.7 vs. 31.5%). Pain and dypsnoea were common in both settings and they concluded that ‘palliative care was not optimal in either setting’ (p. 808).

Other authors found that the majority of patients (up to 95%) end-up requiring 24 h-care either in long-stay hospital wards or in nursing homes (Luchins & Hanrahan 1993, Lloyd-William 1997, Ahronheim et al. 2000). Ahronheim et al. (1996) found that most patients with advanced dementia are treated in nursing homes, but when acute illness supervenes, they are often transferred to hospitals, where they are at risk of receiving invasive or uncomfortable non-palliative interventions. For example, even though McCarthy et al. (1997) found that the immediate cause of death recorded by autopsy in dementia patients was pneumonia, Fried et al. (1997) found that hospitalisation for pneumonia does not seem to improve outcome in nursing home patients and death and functional deterioration had been reported to be more frequent in hospitalised patients than in patients treated in nursing homes.

It is perhaps with this in mind that consideration should be given to the most appropriate place in which to provide palliative care. Campbell and Guzman (2004) suggested that one way to achieve this is if hospitals with expertise in care at the end-of-life share their knowledge with the referring nursing homes to share the principles of best practice.

**Recommendations for research**

Palliative care for the person with dementia has been a relatively neglected topic in relation to policy, planning, practice development and training within the UK (Cox & Keady 1999). Little is known about the needs of people who die from non-malignant diseases, the adequacy of existing services or the effectiveness of specialist palliative care for these patients.

Although there has been considerable work done in USA on the needs of patients with end-stage dementia, we do not know how transferable this is to the UK. It is crucial therefore that research is done within the UK across a range of settings to identify the palliative-care requirements of this vulnerable patient group.

The introduction of care pathways is one way to promote improved care for this patient group. But the use of pathways such as the Liverpool Care Pathway (LCP) (Ellershaw & Wilkinson 2003), supported in England by the Department of Health’s End of Life initiative (Department of Health 2003b), is still very much in its infancy and more research is needed to establish whether patients with dementia are set to benefit from this approach. Another area to consider is whether earlier identification of dementia patients and subsequent monitoring of their ongoing care by registration on the Gold Standards Framework (GSF) register (Thomas 2003), will reduce inappropriate hospital admissions.

**Recommendations for practice**

The findings of this review indicate several ways colleagues across healthcare disciplines can work together to enhance the quality of care of older people in the end stages of dementia. These include:

- accuracy in prognostication and sensitive communication of the diagnosis
- an acknowledgement of the potential influence of the personal belief and value systems of the healthcare team
- improved, timely and appropriate communication including the place of advanced directives
- the reconsideration of aggressive medical treatments
- the need for professionals, carers and where possible patients to work together to plan appropriate and individualised care
- the need for multi-disciplinary ways of working
- a reconsideration of the most appropriate place for delivery of end-of-life care
- an acknowledgement of the right of all older people dying from end-stage dementia to have access to high quality specialist palliative care services.

The accusation that specialist care is ‘five star care for the few’ (Field 1994) is, it could be argued, a very real spectre looming over the whole mission of providing high quality palliative care for older people (Seymour et al. 2001). This care is often constrained by the different paradigms in which we work (Downs et al. 2006) with related professions often emphasising different aspects of care. Therefore, there is a need to develop partnerships in care, to be more proactive and to look critically at the skills and knowledge needed to provide palliative care in a range of settings.

Where there are significant gaps in professional knowledge, skills and expertise, there is an opportunity to cross-fertilise the fields of dementia care for the benefit of all concerned (Burgess 2004). Hospital palliative care teams, through offering specialist advice, can improve the care of many non-cancer patients (Kite et al. 2001). In addition, using the Liverpool Care Pathway (Ellershaw & Wilkinson 2003) focuses on the specific needs of each patient and their family, to ensure that symptoms are assessed, managed and monitored systematically in accordance with evidence-based guidelines.
Conclusion

The management of dementia is becoming a major national and international public health concern because increased longevity places more individuals at risk of developing this disease. Furthermore, Sampson et al. (2006a, p. 31) in their systematic review of UK trials investigating the efficacy of palliative care for older people with dementia, concluded that there is now ‘equivocal evidence of the efficacy for a palliative model of care in dementia’. This review has reinforced the importance of providing appropriate palliative care to individuals suffering from end-stage dementia and some of the barriers to extending such specialist palliative care provision. These include concerns that such an expansion might lead to skills and funding shortages and, in turn, compromise the ability of existing specialist palliative-care teams to provide care to cancer patients. Clinicians and patient groups caring for patients with advanced dementia must work together with specialist palliative-care services and health commissioners to develop, fund and evaluate appropriate cost-effective services which meet patient and family needs. If this is achieved these improvements have the potential to increase quality of life, reduce hospital length of stay and the use of non-beneficial resources. Last and most importantly, terminally ill patients suffering from dementia will therefore not be subjected to protracted, potentially uncomfortable and undignified deaths.

Contributions

Study design: DB; data collection and analysis: DB and manuscript preparation: BD, JD.

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