End of life care for community dwelling older people with dementia: an integrated review

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Objective: To review the evidence for end-of-life care for community dwelling older people with dementia (including those resident in care homes).

Design: An integrated review synthesised the qualitative and quantitative evidence on end-of-life care for community dwelling older people with dementia. English language studies that focused on prognostic indicators for end-of-life care, assessment, support/relief, respite and educational interventions for community dwelling older people with dementia were included. A user representative group informed decisions on the breadth of literature used. Each study selected was screened independently by two reviewers using a standardised check list.

Results: Sixty eight papers were included. Only 17% (12) exclusively concerned living and dying with dementia at home. Six studies included direct evidence from people with dementia. The studies grouped into four broad categories: Dementia care towards the end of life, palliative symptom management for people with dementia, predicting the approach of death for people with dementia and decision-making. The majority of studies were descriptive. The few studies that developed dementia specific tools to guide end of life care and outcome measures specific to improve comfort and communication, demonstrated what could be achieved, and how much more needs to be done.

Conclusions: Research on end-of-life care for people with dementia has yet to develop interventions that address the particular challenges that dying with dementia poses. There is a need for investigation of interventions and outcome measures for providing end-of-life care in the settings where the majority of this population live and die. Copyright © 2009 John Wiley & Sons, Ltd.

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Introduction

There is an increasing policy interest in the needs of people with dementia (Department of Health, 2009) and end-of-life care for older people with long-term conditions (World Health Organisation, 2004; National Council for Palliative Care, 2006; Department of Health, 2007). Professional and policy guidance on care for people with dementia nearing the end of life emphasise the importance of advance care planning, co-ordinated working between health and social care, and the adaptation of palliative care frameworks and
tools for people with long term conditions (Ellershaw et al., 1997; Alzheimer Europe, 2006, 2008; Department of Health, 2008).

Currently one in 14 people of the UK over the age of 65 has a form of dementia, rising to one in six of those over 85. Dementia is one of the main causes of disability in later life (World Health Organisation, 2003). People diagnosed with dementia do not necessarily die from dementia but will die with it (Vallely et al., 2006). The life expectancy for someone diagnosed from onset of symptoms is on average 4.5 years but can be as long as 10.7 years, depending on age at the time of diagnosis and the presence of co-morbidities, (Xie et al., 2008). In the UK, a third of all people with dementia live in a care home and two-thirds in their own homes (Alzheimer’s Society, 2007). Forty per cent of older people with dementia will die at home or in a care home environment that has neither on-site nursing nor access to specialist palliative care services (Kay et al., 2000; McDonald and Cooper, 2006). In the USA, over half of people with dementia died in a nursing home (Mitchell et al., 2005). Reviews of evidence to date have drawn heavily on evidence from settings where there is access to medical and specialist palliative care services for this population (Coventry et al., 2005; Hughes et al., 2005; Robinson et al., 2005; Sampson et al., 2005; Zwakhalen et al., 2006; Birch and Draper, 2008). Generalist palliative care frameworks may increase awareness of the issues for people with dementia. However, for those who are living at home or in care homes, definitions of end-of-life are often imprecise, and it is unclear whether generalist palliative care frameworks address the needs of people with dementia (Goodman et al., 2003; Downs et al., 2006; Shipman et al., 2008).

This paper reports on an integrated review of research that synthesised the qualitative and quantitative evidence on end-of-life care for community dwelling older people (including those living in care homes) with dementia, addressing the question: What is the evidence for palliative care interventions for community dwelling older people (including those resident in care homes) with dementia?

**Methods**

Published and unpublished English language studies on palliative care for older people with dementia, produced between 1985 and 2006 were included. Published studies were identified through electronic data bases of papers in peer reviewed journals: AMED, ASSIA, BNI, CareData, CINAHL, EBMR, EMBASE, HMIC, IBSS, Medline, PSychINFO and Social Science Citation index. The Cochrane database and older people and dementia specialist libraries, for example the Alzheimer’s Society library and Dementia Services Development library, were reviewed. Online data bases of unpublished evidence and ‘grey’ evidence (e.g. SIGLE, research registers, conference proceedings) were systematically examined, and hand searches undertaken of non-indexed journals and frequently cited journals. The search included the following terms: palliative care, terminal care, attitude to death, or dying, end-of-life care, comfort care, symptom control, end stage disease, living will, advance directive, palliative adj (treatment or care) and subject headings for dementia: Alzheimer’s disease, dementia, neuro-degenerative diseases, Parkinson’s disease, aphasia. Key authors, individuals and agencies with a remit for dementia care were contacted to identify current work and unpublished reports. Lateral searching ‘techniques and the related articles’ option on data bases were also used, an approach particularly recommended when searching for studies on complex interventions (Greenhalgh et al., 2004). Studies included were those that focused on prognostic indicators for end-of-life care, assessment, support/relief, respite and educational interventions for older people with dementia in primary care settings/community dwelling settings (defined as patients’ own home), care homes, (defined as a long term residential facility for older people that offers personal care and may or may not have on site nursing provision) and settings staffed by or with links to primary care. Studies were excluded when they were:

1. A synthesis of expert opinion.
2. Empirical studies that were hospital-based.
4. On people with dementia under 65 years old.
5. Either end of life studies not specific to dementia or dementia studies but not at the end of life.

As part of the development of the review methodology, a user representative group was convened. It consisted of eight family carers of people who had either recently died from, or were suffering from symptoms of advanced dementia, three user representatives from older people and dementia charities, and five health professionals involved in end-of-life care for people with dementia. This was a self-selecting group that had responded to an invitation sent out through a local network of health professionals, academics and members of the public interested in older people’s research (AgeNet). The group’s discussions informed
the researchers’ decisions on the breadth of sources for the literature. They also identified from their perspective the key research questions and research priorities for people with dementia at the end of life that were incorporated into the review. For the purposes of the review interventions were defined as (a) those activities that could influence how end of life was recognised and (b) care provided for people with dementia at the end of life. This included descriptive studies if the focus and findings could be interpreted as having the potential to inform clinical decision making.

Electronic search results were downloaded into bibliographic software screened using the predefined inclusion criteria and all members of the multidisciplinary research team (VD, KF, ES, MB, SI, MBi) reviewed potentially relevant citations. These were then screened independently by two reviewers (JW, CG, CE). The methodological quality of studies was judged using criteria based on those of the Cochrane Collaboration and the Cochrane EPOC group (EPOC, 2005; Higgins and Green, 2006).

### Results

Over 5000 possible research publications were identified. On initial reading of the abstracts 292 appeared to meet the inclusion criteria and the full publications were retrieved. Most of these (223) were excluded by the reviewers because they either failed to meet the inclusion criteria of empirical research evidence (103) or were empirical studies but did not describe/evaluate an intervention in dementia care at the end of life for older people in a community setting (120).

Sixty seven papers were included in the final review. Most studies were conducted in North America (61%, n = 41). Thirty per cent (n = 20) reported on European studies (including the UK) and the remainder on studies from Asia and Australia. The majority of studies (64%, 43) had been undertaken in a care home setting. Only 18% (12) exclusively concerned living and dying with dementia at home, while a further six studies included at home care in mixed setting studies (e.g. at home care and hospice care). Six studies included direct evidence from people with dementia (The Anne Mei, 2002; Allen, 2003; Abbey et al., 2004; Shega et al., 2004; Magaziner et al., 2005; Abbey, 2006) as opposed to relying on family carers’ and health professionals’ accounts and/or records of the care. Most studies had purposive or convenience samples. Individual non-experimental studies were the most frequent (58%, 39), followed by descriptive studies (37%, 25). The literature contained two Randomised Controlled Trials (Kovach et al., 2006a, 2006b) and one other experimental study (Abbey et al., 2006). Of those studies that included data on people with dementia (n = 36), sample sizes ranged from 25 to 9264 (median 148); large sample sizes were found in those studies that used secondary analysis of large patient medical record data sets. The papers were further categorised by the type of research question they addressed. This gave four broad categories concerned with: the experience of caring for people with dementia who were dying, how dying in people with dementia is recognised, research on symptom management, and research on decision making about end-of-life care for people with dementia. These were summarised as:

- Dementia care towards the end of life
- Predicting the approach of death for people with dementia
- Palliative symptom management for people with dementia
- Decision making at the end of life

Although inevitably there was some overlap with studies falling into more than one category the highest proportion of papers (n = 28, 41%) focused on describing dementia care towards the end of life. Predicting the approach of death for people with dementia (18%, 12) was a particular focus of US studies influenced by US financial eligibility criteria for time limited hospice care. Studies addressing practitioners’ and family carers’ decision making at the end-of-life, and the use of advanced care directives accounted for 25% (17) of papers. Thirteen papers (19%) focused on pain and behavioural symptoms, measurement of discomfort and the effects of withholding nutrition and hydration. Practitioner education, design of care settings psycho–social issues or spirituality were addressed within some of the studies reviewed but not as discrete areas of research (e.g. Albinsson and Strang, 2003; Abbey et al., 2006). The evidence will now be considered in turn for each of the categories.

### Dementia care towards the end of life

This section considers what is known about how culture and context informs how care is provided and the overall experience of end-of-life care for older people with dementia and their family carers.

The variation between different countries’ approaches to end-of-life care can be attributed to how end-of-life care is organised (particularly in
nursing homes) and the legal and social understanding of end-of-life decision making, which in turn reflects both professional and family values (Helton et al., 2006). A Dutch study of 35 patients concluded that because the clinical course of dementia was considered normal, artificial administration of fluids and food was rare (The Anne Mei, 2002). The interpretations of the patient’s quality of life by their care providers were often culturally determined and could be more significant in shaping care than living wills and policy agreements. Longitudinal studies of antibiotic treatment following onset of pneumonia in people with dementia in the USA and the Netherlands, demonstrated a higher mortality from pneumonia for people with dementia in the Netherlands than in the USA (Mehr et al., 2003, Steen et al., 2004). A Spanish prospective study with an unrepresentative sample of community dwelling people with advanced dementia, found that using artificial nutrition was strongly associated with mortality (Varez Fernandez et al., 2005). One US study also found that there were rural–urban differences between residents with severe dementia at the end of life with a greater use of aggressive treatment for urban subjects (Gessert et al., 2001). Studies that compared end-of-life care for people with dementia between countries and settings signify how location and systems of care as well as patient symptoms and physician responses influence patient outcomes.

Notwithstanding cultural differences, studies from North America, Europe and Australia indicated that people with dementia are likely to receive a poorer quality of care than those without dementia. There are a few studies demonstrating interventions that improve this situation. People with dementia living in nursing homes experience fewer adverse symptoms and improved levels of comfort when there are dementia specific, structured, approaches to providing care, with specialist support and staff education, (Kovach et al., 1996, 1999; Bekelman et al., 2005). However, when compared with other patient groups, people with dementia receive less pain relief and fewer medical services, and any decisions to forgo hospital admission are not made until death is imminent (McCarthy et al., 1997; Burton et al., 2001; McCormick et al., 2001; Haydar et al., 2004; Lamberg, et al., 2005; Hirakawa et al., 2006a, 2006b). Barriers to the provision of quality care for people with dementia at end of life include the lack of any valid measurement of quality of care and quality of life, and of appropriate interventions (Blasi et al., 2002). Studies show that, even with the use of clinical assessment tools it is difficult to recognise when someone with dementia is dying (Mitchell et al., 2004a, 2004b; Brandt and Ribe, 2005) and, also, that staff lack confidence in the assessment and management of care at the end of life for people with dementia (Moss et al., 2002).

For people with dementia living at home or in settings where family members have ongoing contact and involvement, the role and contribution of carers is crucial. Studies indicate that family carers of older people with dementia who are approaching the end of life have different but equivalent needs to carers of patients dying from other diseases (Schulz et al., 2003). Rather than the physical aspects of the end stage of dementia, carers’ experiences and responses are shaped by the dementia-related behaviours and the experience of prolonged loss, including loss of choice and control when someone moves into a care home or is transferred to hospital (Loos, 1997; McCarthy et al., 1997; Albinsson and Strang, 2003a, 2003b; Bond et al., 2003; Bowes and Wilkinson, 2003; Diwan et al., 2004). Studies highlight the mixed feelings caregivers experience at the death of the person with dementia, the importance of a ‘goodbye moment’ and the misconception that all the grieving has already been done by the time a person with dementia dies (Almberg et al., 2000; Adams, 2004). Although when there has been a protracted period of caring, a study of 217 family carers found relief is a significant emotion when the person with dementia dies, with only a minority (14%) requiring bereavement related services (Schulz et al., 2003). When the older person with dementia is in a care home, factors that improve carer experience and satisfaction, particularly around end-of-life care decision making are: giving structured time to communication, addressing issues of resident comfort, avoidance of tube feeding and care in a specialist unit (Engel et al., 2006).

Predicting the approach of death for people with dementia

Recognising when a person stops living with dementia and starts dying from it, and the prediction of survival time, can influence decisions to involve specialist palliative care services and the release of resources. It can also influence decision making about the benefit of transferring patients to acute services. A failure to recognise that someone is dying can result in potentially distressing and unnecessary hospital admissions (Lamberg et al., 2005). A number of studies indicate that health professionals are not skilled at recognising the end stages. A US study of 883 nursing home residents found that one per cent of people with
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Dementia were recorded as having a life expectancy of less than six months, but 71% of them died during this period (Mitchell et al., 2004a). A Korean study (Suh et al., 2004) tested the hypothesis that mortality in people with dementia is higher in care homes than in the community and found no difference in mortality rate. Predictors of death were age, global deterioration, duration of disease, the presence of hallucinations, wandering and depression. A five year longitudinal study of 102 community dwelling people with dementia found dementia associated with excess mortality; major causes of death related to dementia were cachexia, dehydration and pneumonia (Boersma et al., 1999). However, two cohort studies indicated that the severity of dementia itself, independent of the presence of co-morbidities, was enough to predict the end of life (Dooneief et al., 1996; Van Dijk et al., 1996).

Little consensus was found about the value of prognostic indicators for people with dementia. Several studies tested and validated scales to predict survival. Contextual factors such as the use of tube feeding and less aggressive care plans (Hanrahan et al., 1999; Lapane et al., 2001) plus the inability of some scoring systems to discriminate between underlying morbidity and different disease trajectories, gender differences, and disabilities mean that existing tools and guidelines need further validation and refinement (Gambassi et al., 1999; Mitchell et al., 2004a, 2004b; Magaziner et al., 2005). A small descriptive study argued that the use of hospice guidelines for people with dementia were useful for identifying survival time of less than six months (Hanrahan et al., 1999), but a study that reviewed the notes of 165 people with dementia admitted to a community-based hospice found that only 64% of people who met criteria for hospice care died within six months of admission. It concluded that advanced age, anorexia and level of function were more useful prognostic indicators than existing guidelines (Schonwetter et al., 2003).

Palliative symptom management for people with dementia

This section considers what is known about the management of pain and discomfort at the end of life.

Compared to those with other conditions patients with dementia are more likely to experience a variety of symptoms including persistent pain, and are more likely to be untreated, in the last six months of life (McCarthy et al., 1997). More recently, Hirakawa et al. (2006a), in a retrospective survey in Japan, compared the last 48 hours of life of people with dementia (n = 98) with patients at home without dementia (n = 112) and compared their experience of symptoms and the end-of-life care they received. After controlling for age and other differences in baseline characteristics, dementia was determined to be a significant independent predictor of uncontrolled pain.

Research on the assessment of pain for people with end stage dementia is limited and has focused on the ability of carers to predict pain (Shega et al., 2004) and the validity and perceived usefulness of different pain assessment tools for end-of-life care (Abbey et al., 2004). Van Lersel et al. (2006) asked 185 care providers to compare two pain assessment tools (Abbey and PAINAD) with 157 older people who could not verbally express their experience of pain. Approximately half of care providers evaluated both scales as being good measures of pain and easy to use, and identified three indicators as the most valuable for measuring pain: facial expression, vocalisation and body language.

A series of studies developing and testing an assessment tool for discomfort in dementia (ADD) in people with late stage dementia in nursing homes, used analgesia and provision of non-pharmacological comfort intervention as outcome measures (Kovach et al., 1999; Kovach et al., 2001). Overall findings suggested that use of the tool could improve symptom recognition and administration of analgesia although its uptake and use by care staff was variable. Later work by the same team (Kovach et al., 2006a, 2006b) tested a five step clinical protocol to promote comfort and reduction of behavioral symptoms of psychological distress with 57 nursing home residents. Whilst treatment response to positive assessment was effective for 86% of participants, 70% of participants received a positive assessment, but no treatment. Non-pharmaceutical interventions were effective in reducing discomfort for 62% of participants, and analgesics effective for 75% of participants. The study demonstrated more effective use of analgesia and less discomfort in the intervention group. This work, and that of Abbey et al. (2004), highlighted the importance of structured ways of working that combine educational support for care workers with the development of interventions that are specific for end-of-life care for people with dementia. These studies were based in nursing homes and relied on effective cross-disciplinary working.

We found no research in these settings that focused on different ways of using nutrition and fluids as a means of providing comfort and enhanced quality of life. Although there is some evidence to suggest that withdrawing artificial hydration and nutrition does not
increase discomfort (Chouinard et al., 1998; Pasman et al., 2004, 2005).

Decision making at the end of life

Advanced care planning represents an opportunity to involve people with dementia and their carers in decision making and to achieve care that aims to be centred on the individual’s wishes rather than the assumptions of the service. Gjerdingen et al. (1999) in a survey of 84 older people living at home and in transitional care found that three quarters would not want aggressive interventions, including tube feeding, if they had dementia. In a cohort study of 78 people with dementia across five US nursing homes, Allen (2003) found that most residents could state a simple treatment preference (82.4%), but a sizable number did not retain capacity to understand treatment alternatives or appreciate the consequences of their choice. The authors concluded that measures of cognitive ability offered limited information about a resident’s capacity for decision making and recommended that interventions to engage residents and families in structured discussions for end-of-life planning were needed.

Carer involvement in advance care planning and decision making

Little is known about how carers engage with anticipating the end-of-life for people with dementia (Roscoe and Cohen, 1999), although family carers are more likely than professionals to want interventions to support life (Coetzee et al., 2003). A robust qualitative study with 28 carers of people with dementia demonstrated the complexity and stages of the decision making process. It concluded that families need assistance to process difficult and painful emotions, to understand the disease trajectory, to appreciate that some decisions might impede a natural death and to grasp the available comfort and palliative care options (Forbes et al., 2000). Nevertheless, carers believe that advanced directives help (Bekelman et al., 2005). The presence of an advance care plan and perceptions of a patient’s quality of life may affect carers’ decision making about interventions to prolong life. However, the review demonstrated how contextual factors such as level of education, rural or urban settings and nationality all influence individuals’ responses to decision making about place of care and interventions at the end of life (Caron et al., 2005a, 2005b; Chen et al., 2006; Gessert et al., 2006). Very few studies have engaged with how carers interact with professionals in the decision-making process, nor have they described what is required for effective communication (Caron et al., 2005b) even though it is clear that how physicians resolve and negotiate patient and family preferences regarding care appears to directly influence patient outcomes (Helton et al., 2006). In the absence of agreed guidelines, and advance care plans, decision making for people with dementia at the end of life is shaped by differences in religious beliefs, professional training, understanding of the disease, what is meant by palliative care, perspectives of other patients, culture and beliefs (Luchins and Hanrahan, 1993; Cavalieri et al., 2002; Hinkka et al., 2002; The Anne Mei, 2002; Lacey, 2005; Haydar et al., 2004; Rurup et al., 2006).

Despite discussion and exploration of the feasibility of introducing advance care planning into long term care for people with dementia (Volicer et al., 2002), we found no studies that evaluated the impact of advanced care directives on the overall approach to end-of-life care and its related outcomes of place of death, treatments received and carer involvement in and satisfaction with the home or care home environment.

Studies on professionals’ decision making for people with dementia at the end of life similarly highlight a mix of views and approaches. One review, of 929 deaths over a year in a nursing home, found that decisions by attending Dutch physicians to forego artificial administration of feeding and fluids were more likely for residents with perceived poor quality of life and where palliation was the aim of treatment. Relatives and competent residents were involved in the decision to forego treatment, but not relatives of residents lacking capacity (Onwuteaka-Philipsen et al., 2001). One study, also from the Netherlands, reviewed with physicians the notes of 135 people in nursing homes who died from pneumonia after antibiotics had been withheld, and found that the intention to hasten death was evident in 53% of the cases, and that the action would hasten death was considered in 41% (Van der Steen et al., 2005). It is significant that the two studies on professional decision making we found were both from the Netherlands where medical staff are on hand. We found no studies that considered how family physicians, community nurses and care home staff become involved in decision making for this population.

Discussion

The majority of older people with dementia spend the last months and years of their life at home or in a care
home. A preoccupation with decision making and care provision in the last days of life, has meant that little research has focused on the detail of the experiences of patients with dementia and their carers’ leading up to the last days of life, or considered what supports and inhibits the provision of end-of-life care at home or in settings that have intermittent access to specialist palliative care support. Without a better understanding of the interactions between patient symptoms, caregiver factors, cultural and ethnic differences, and different types of collaborative working, it is likely that research in this area will continue to be atheoretical and insensitive to context.

The majority of studies were not experimental in design but descriptive, so could only begin to address aspects of care that should be stopped and deficits in existing approaches to care. Downs et al. (2006) have noted how end-of-life care for people with dementia has yet to develop interventions that address the particular challenges that dying with dementia poses. The few studies that did develop dementia specific tools to guide end-of-life care and outcome measures specific to improve comfort and communication demonstrated both what could be achieved and how much more needs to be done. That none of this work was undertaken in patients’ homes or involved family physicians and community nursing staff is significant and of concern.

There were limitations to the review. The absence of a shared understanding of how end of life is recognised, or at what point end of life is defined for people with dementia, means that research that focused on improving symptom assessment for people with advanced dementia, on needs assessment in care homes, and on communication and the involvement of people with dementia in decision making were not included in the review (Fossey et al., 2006; Hancock et al., 2006; Zwakhalen et al., 2006). Data extraction ceased in 2006, however a rapid review of research and reviews published up till 2008 (Birch and Draper, 2008; Di Giulio et al., 2008; Lorenz and Lynn, 2008) indicate that the research focus and methods and findings discussed in this paper have not dramatically changed, and that there are still very few intervention studies that include people with dementia who are living at home or in a care home.

This review complements the work of others that have demonstrated how fragmented and descriptive research on end-of-life care for people with dementia is regardless of setting, and the absence of work that is dementia specific (Hughes et al., 2007). What this review starkly illustrates however, is the lack of interventions and outcome measures for providing end-of-life care in the settings where the majority of this population live and die.

Key Points
- The majority of older people with dementia live and die at home or in a care home.
- Policy guidance and end-of-life initiatives, though laudable, have outstripped the available evidence on end-of-life care for people with dementia and their carers that live at home and in care homes.
- Without a better understanding of the interactions between patient symptoms, caregiver factors, cultural and ethnic differences, and different types of collaborative working, it is likely that research in this area will continue to be atheoretical and insensitive to context.

Conflict of interest
None declared.

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