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

Deborah Birch
BSc (Hons) Gerontological Nursing, RGN
Liverpool Care Pathway Co-ordinator
United Lincolnshire NHS Trust
Greetwell Road
Lincoln
Lincolnshire
LN2 5QY
Email: deborah.birch@ulh.nhs.uk
Tel: 01522 512512 Ext. 2555

Jan Draper
PhD, BSc (Hons), RGN
Programme Director
RCN Institute
20 Cavendish Square
LONDON
W1G 0RN
Email: jan.draper@rcn.org.uk
Tel: 01430 424158

ABSTRACT

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 the 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 the UK and was 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.

Keywords

Nurses, nursing, Palliative care, end-of-life, dementia.

Comment [A1]: Please provide but keep within 300 word limit.
Done

INTRODUCTION

Demographic trends show that older people living in the United Kingdom (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 the UK alone, 83.5% of deaths are in 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 5 in those over the age of 85 and is set to become even more prevalent (Luchins & Hanrahan 1993). About 100,000 people with dementia die each year in the UK (Bayer 2006). In 2001, the annual health and social care service provision for people with dementia in England and Wales was estimated to cost between £9.5 and £ 13.5 billion (McNamee 2001).

Dementia is now recognized as a progressive terminal illness for which there is currently no cure (Shuster 2000, Lloyd-Williams & Payne 2002, Burgess 2004) but its progression varies. The prognosis for a patient may range from two to over 15 years (Lloyd-Williams 1996) with the end-stage of the illness lasting as long as two or even three years (Shuster 2000).

The National Health Service (NHS) Confederation (2005) acknowledged that in addition to the care of patients with malignancy, end-of-life care should extend to long term conditions such as heart disease, neurological conditions, general frailty and dementia. This recognition of the need for good quality end-of-life or palliative care has increased over recent years with greater resources being committed by the UK Government (DoH 2000, 2003a).

The National Service Framework for Older People (DoH 2001) supported the use of better quality end-of-life care for older people in particular, noting that many older people found that palliative care services had not been available to them. *A New Ambition for Old Age* (DoH 2006) identifies 10 programmes one of which discusses the three palliative care models now considered to be best practice: Gold Standards Framework (GSF) (Thomas 2003), Preferred Place of Care (PPC) (Storey *et al*. 2003) and the Liverpool Care Pathway (LCP) (Ellershaw and Wilkinson 2003).

From its infancy the palliative care movement has been 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, 8 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 was identified and are now discussed.

Prognostication

Prognosis

Realistic prognoses are essential to allow patients and their carers to realistically 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 impairment may hinder treatment due to 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 the USA, they examined the survival of patients with end-stage dementia by monitoring 216 patients over a 6 month period

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, Harahan *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 (Murtagh *et al*. 2004). Indeed, Albinsson and Strang (2002 p.169) suggest that 'the fact that dementia is not seen as a palliative illness is probably due to the long period of time that often elapses between detection of the illness and 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 (Murray *et al*. 2005) (Figure 1). Stewart & 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 as 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. 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 (Hinnka *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 continually (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.

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).

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 *et al*. (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 a 12 month period (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 were 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 emphasize 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. Whilst 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 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 the UK, originating predominantly from America, 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 the 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). Hinnka *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.

The need for improved, timely and appropriate communication has been, therefore, a key theme throughout the literature with many authors placing significant importance on its role and value in effective end-of-life planning for dementia (Ahronheim *et al*. 1996, Maguire *et al*. 1996, McCarthy *et al*. 1997, Morrison & Siu 2000, Volicer *et al*. 2001, Hinkka *et al*. 2002, Lloyd-Williams 2002, Michel *et al*. 2002, Volicer *et al*. 2003).

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*. 2004). 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 versus 20% without). However, significantly more patients were documented as having measurement of blood gases (80% versus 58%; p=0.024) and insertion of urinary catheters (77% versus 57%; p=0.035) and nasogastric tubes (40% versus 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% versus 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 America, examined the frequency of palliative and aggressive treatments delivered during the previous 6 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 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 emphasized 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 dypsnoea, 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*. (2005) call the 'disadvantaged dying' (p.135).

In a randomized 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, so 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 America 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*. (2004) conducted a retrospective cohort study in the USA of older people with dementia dying in either nursing home or home care settings. They found that only 5-7% of those resident 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% v 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 hour care either in long-stay hospital wards or in nursing homes (Luchin & 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 hospitalized 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 & 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 the 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 Pathways (LCP) (Ellershaw & Wilkingson 2003), supported in England by the Department of Health's End of Life initiative (DoH 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 in which 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

Manuscript preparation BD & JD

References

Absolon, C. (1998) My father died of dementia… *Palliative Medicine,* 12, pp. 195-196.

Addington-Hall, J., Fakhoury, W. and McCarthy, M. (1998) Specialist palliative care in non-malignant disease, *Palliative Medicine,* 12, pp. 417-427.

Ahronheim, J., Morrison, S., Baskin, S., Morris, J. and Meier, D. (1996) Treatment of the Dying in the Acute Care Hospital: Advanced Dementia and Metastatic Cancer, *Arch Intern Med*, 156, pp. 2094-2100.

Ahronheim, J., Morrison, S., Morris, J., Baskin, S. and Meier,D. (2000) Palliative Care in Advanced Dementia: A Randomized Controlled Trial and Descriptive Analysis, *Journal of Palliative Medicine,* 3(3), pp. 265-273.

Albinsson, L. and Strang, P. (2002) A palliative approach to existential issues and death in end-stage dementia care, *Journal of Palliative Care*, 18(3), pp.168-174.

Aminoff, B. and Adunsky, A. (2004) Dying dementia patients: Too much suffering, too little palliation, *American Journal of Alzheimer's Disease and Other Dementias,* 19(4), pp. 243-247.

Aminoff, B. Z. and Adunsky, A. (2006) Their last 6 months: Suffering and survival of end-stage dementia patients, *Age and Ageing*, 35(6), pp. 597-601.

Bayer, A. (2006) Death with dementia - the need for better care, *Age and Ageing,* 35, pp. 101-102.

Burgess, L. (2004) Addressing the palliative care needs of people with dementia, *Nursing Times*, 110(19), pp. 36-39.

Campbell, M. and Guzman, J. (2004) A proactive approach to improve end-of-life care in a medical intensive care unit for patients with terminal dementia, *Critical Care Medicine,* 32(9), pp. 1839-1843.

CancerStats (2005) *Mortality UK Cancer Research,* CancerStats, London.

Caron, C. D., Griffith, M. and Arcand, M. (2005) Decision making at the end of life in dementia: How family caregivers perceive their interactions with health care providers in long-term care settings, *Journal of Applied Gerontology*, 24 (3), pp. 231-247.

Carpenter, M. (2004) The role of the physician for the elderly in the assessment, diagnosis and treatment of patients with dementia in Curran, S. and Wattis, J. (Eds) *Practical Management of Dementia; a*

multi-professional approach, Oxford, Radcliffe Medical Press Ltd, pp. 87-98.

Christakis, N. A. and Lamont, E. B. (2000) Extent and determinants of error in doctors' prognoses in terminally ill patients: prospective cohort study, *British Medical Journal,* 320, pp. 469-72.

Coventry, P., Grande, G., Richards, D. and Todd, C. (2005) Prediction of appropriate timing of palliative care for older adults with non-malignant life-threatening disease: a systematic review, *Age and Ageing*, 34, pp. 218-227.

Cox, S. and Keady, J. (1999) *Younger People with Dementia: Planning and Practice and Developmen,* London, Jessica Kingsley Publishers.

Davies, E. and Higginson, I. (Eds) (2004) *Better palliative care for older people,* Denmark, World Health Organisation.

Department of Health (2000) *The NHS Cancer Plan: A plan for Investment, A Plan for Reform,* Department of Health, London.

Department of Health (2001) *National Service Framework for Older People,* Department of Health, London.

Department of Health (2003a) *Building on the Best: Choice Responsiveness and Equity in the NHS,* Department of Health, London.

Department of Health (2003b) *NHS End of Life Care Initiative*, Department of Health, London.

Department of Health (2006) *A New Ambition for Old Age: Next Steps in Implementing the National Service Framework for Older People*, Department of Health, London.

Downs, M., Small, N. and Froggatt, K. (2006) Explanatory models of dementia: links to end-of-life care, *International Journal of Palliative Nursing*, 12 (5), pp. 209-13.

Ellershaw, J. and Wilkinson, S. (2003) *Care of the Dying: a Pathway to Excellence,* Oxford, Oxford University Press.

Engel, S. E., Keily, D. K. and Mitchell, S. L. (2006) Satisfaction with end-of-life care for nursing home residents with advanced dementia, *Journal of the American Geriatrics Society*, 54(10), pp. 1567-1572.

Evers, M., Purohit, D., Perl, D., Khan,K. and Marin, D. (2002) Palliative and Aggressive End-of Life Care for Patients With Dementia, *Psychiatric Services*, 53(5), pp. 609-613.

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

Field, D. (1994) Palliative medicine and the medicalisation of death, *European Journal of Cancer Care,* 3, pp. 58-62.

Forbes, S., Bern-Klug, M. and Gessert, C. (2000) End-of-life decision making for nursing home residents with dementia, *Journal of Nursing Scholarship*, 32 (3), pp. 251-258.

Fried, T. R., Gillick, M. R. and Lipsitz, L. A. (1997) Short-term functional outcomes of long-term care residents with pneumonia treated with and without hospital transfer, *Journal of the American Geriatric Society,* 45, pp. 302-306.

Hallberg, I. (2006) Palliative care as a framework for older people's long-term care, *International Journal of Palliative Nursing,* 12(5), pp. 224-229.

Hanrahan, P. and Luchins, D. J. (1995) Feasible criteria for enrolling end-stage dementia patients in home hospice care, cited in Coventry, P., Grande, G., Richards, D. and Todd, C. (2005) Prediction of appropriate timing of palliative care for older adults with non-malignant life-threatening disease: a systematic review, *Age and Ageing*, 34, pp. 218-227.

Hanrahan, P., Raymond, M., McGowan, E. and Luchins, D. (1999) Criteria for enrolling dementia patients in hospice: a replications, cited in Coventry, P., Grande, G., Richards, D., Todd, C. (2005) Prediction of appropriate timing of palliative care for older adults with non-malignant life-threatening disease: a systematic review, *Age and Ageing*, 34, pp. 218-227.

Head, B. (2003) Palliative care for Persons with Dementia, *Home Healthcare Nurse*, 21(1), pp. 53-60.

Hedera, P. (2001) Ethical principles and pitfalls of genetic testing for dementia, *Journal of Geriatric Psychiatry and neurology,* 14(4), pp. 213-21.

Hinkka, H., Kosunen, E., Metsanoja, R. and Kellokumpu-Lehtinen, P. (2002) Decision making in terminal care: a survey of Finnish doctors' treatment decisions in end-of-life scenarios involving a terminal cancer and a terminal dementia patient, *Palliative Medicine*, 16, pp. 195-204.

Keene, J., Hope,T., Fairburn, C. and Jacoby, R. (2001) Death and dementia, *International Journal of Geriatric Psychiatry*, 16, pp. 969-974.

Kirk, P., Kirk, I. and Kristjanson, L. (2004) What do patients receiving palliative care for cancer and their families want to be told? *British Medical Journal*, 328, pp. 1343-7.

Kite, S., Jones, K. and Tookman, A. (2001) A specialist palliative care and patients with non-cancer diagnosis: the experience of a service, *Palliative Medicine,* 15, pp. 413-418.

Lloyd-Williams, M. (1996) An audit of palliative care in dementia, *European Journal of Cancer Care,* 5, pp. 53-55.

Lloyd-Williams, M. and Payne, S. (2002) Can multidisciplinary guidelines improve the palliation of symptoms in the terminal phases of dementia?, *International Journal of Palliative Nursing, 8(8), pp. 370-5.*

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

Luchins, D. J., Hanrahan, P. and Murphy, K. (1997) Criteria for enrolling dementia patients in hospice, cited in Coventry, P., Grande, G., Richards, D. and Todd, C. (2005) Prediction of appropriate timing of palliative care for older adults with non-malignant life-threatening disease: a systematic review, *Age and Ageing*, 34, pp. 218-227.

Lynn, J. (2000) Learning to care for people with chronic illness facing the end of life, *JAMA,* 284(19), pp. 2508-2511.

Maguire, C., Kirby, M., Coen, R., Coakley, D., Lawlor, B. and O'Neill, D. (1996) Family members' attitudes toward telling the patient with Alzeheimer's disease their diagnosis, *British Medical Journal,* 313, pp. 529-530.

Mast, K., Salama, M., Silverman, G. and Arnold, R. (2004) End-of-life in Treatment Guidelines for Life-Limiting Disease, *Journal of Palliative Medicine,* 7(6), pp. 754-773.

McCarthy, M., Addington-Hall, J. and Altmann, D. (1997) The Experience of Dying with Dementia: A Retrospective Study, *International Journal of Geriatric Psychiatry,* 12, pp. 404-409.

McNamee, P. (2001) Cost of dementia in England and Wales in the 21st century. *British Journal of Nursing,* 179, pp. 261-266.

Meyers, B. (1997) Telling patients they have Alzheimer's disease: Important for planning their future and no evidence of ill effects, *British Medical Journal,* 314, pp. 321-322.

Michel, JP., Pautex, S., Zekry, D., Zulian, G. and Gold, G. (2002) End of Life Care of Persons with Dementia, *Journal of Gerontology,* 57(10), pp. M640-M644.

Mitchell, S. L., Keily, D. K. and Hamel, M. B. (2004) Dying with advanced dementia in the nursing home, *Archives of Internal Medicine*, 164(3), pp. 321-328.

Mitchell, S. L., Morris, J. N., Park, P. S. and Fries, B. E. (2004a) Terminal care for persons with advanced dementia in the nursing home and home care settings, *Journal of Palliative Medicine*, 7(6), pp. 808-816.

Morrison, S. and Siu, A. (2000) Survival in End Stage Dementia following Acute Illness, *JAMA*, 284(1), pp. 47-52.

Murray, S. A., Kendall, M., Boyd, K. and Sheikh, A. (2005) Illness trajectories and palliative care, *British Medical Journal,* 330, pp. 1007-1011.

Murtagh, F. E. M., Preson, M. and Higginson, I. (2004), Patterns of dying: palliative care for non-malignant disease, *Clinical Medicine*, 4, pp. 39-44.

National Council for Palliative Care (2007) *Palliative Care Bill: Briefing for peers*, The National Council for Palliative Care, London.

NHS Confederation (2005) *Leading Edge. Improving End of Life Care,* Issue 12, NHS Confederation, London.

Office for National Statistics (2005) *Focus on Older People,* London, The Stationary Office.

Payne, S. and Froggatt, K. (2006) Editorial: Dying in late old age: the final frontier?, *International Journal of Palliative Nursing,* 12(5), pp. 200.

Robinson, L., Hughes, J., Daley, S., Keady, J., Ballard, C. and Volicer, L. (2006) End-of-life care and dementia, *Reviews in Clinical Gerontology*, 15(2), pp. 135-148.

Roger, K. S. (2006) A literature review of palliative care, end of life and dementia, *Palliative and Supportive Care*, 4(3), pp. 295-303.

Rurup, M, L., Onwuteaka-Philipsen, B. D., Pasman, H., Roeline, W., Ribbe, M. W. and van-der-Wal, G. (2006) Attitudes of physicians, nurses and relatives towards end-of-life decisions concerning nursing home patients with dementia, *Patient Education and Counselling*, 61(3), pp. 372-380.

Sachs, G. A., Shega, J. W. and Cox-Hayley, D. (2004) Barriers to excellent end-of-life care for patients with dementia, *Journal of General Internal Medicine,* 19(10), pp. 1057-1063.

Sampson, E. L., Ritchie, C. W., Lai, R., Raven, P. W. and Blanchard, M. R. (2006a) A systematic review of the scientific evidence for the efficacy of a

palliative care approach in advanced dementia, *International Psychogeriatrics*, 17(1), pp. 31-40.

Sampson, E. L., Gould, V., Lee, D. and Blanchard, M. R. (2006b) Differences in care received by patients with and without dementia who died during acute hospital admission: a retrospective case note study, *Age and Ageing,* 35, pp. 187-189.

Seymour, J., Clark, D. and Philp, I (2001) Palliative care and geriatric medicine: shared concerns, shared challenges, *Palliative Medicine*, 15, pp. 269-270.

Seymour, J., Witherspoon, R., Gott, M., Ross, H. and Payne, S. (2005) *Dying in Older Age: End of Life Care,* Policy Press, Bristol.

Shuster, J. L.(2000) Palliative care for advanced dementia, *Clinical Geriatric Medicine,* 16, pp. 373-386.

Steinhauser, K., Christakis, N., Clipp, E., McNeilly, M., McIntyre, L. and Tulsky, J. (2000) Factors Considered Important at the End of Life by Patients, Family, Physicians and Other Care Providers, *JAMA*, 284(19), p.2476.

Stewart, S., McMurray, J. (2002) Palliative care for heart failure. *British Medical Journal.* 325: pp915-916.

Storey, L., Pemberton, C., Howard, A. and O'Donnell, M.A. (2003) Place of death: Hobson's choice or patients choice, *Cancer Nursing Practice,* 2(4), pp. 33-38.

Thomas, K. (2003) *Caring for the dying at home: companions on the journey,* Abingdon, Radcliffe Medical Press Limited.

Visser, G., Klinkenberg, M., Broese van Grenou, M., Willems, D., Knipscheer, C. and Deeg, D. (2004) The end of life: informal care for dying older people and its relationship to death, *Palliative Medicine,* 18(15), pp. 468-477.

Volicer, L. (2001) Management of Severe Alzheimer's Disease and End-of-Life issues, *Clinics in Geriatric Medicine,* 17(2), pp. 377-391.

Volicer, L., Hurley, A. and Blasi, Z. (2001) Scales for Evaluation of End-of-Life Care in Dementia, *Alzheimer Disease and Associated Disorders,* 15(4), pp. 194-200.

Volicer, L., Hurley, A. and Blasi, Z. (2003) Characteristics of dementia end-of-life care across care settings, *American Journal of Hospice & Palliative Care*, 20(3), pp. 191-200.

Von Genten, C. and Twaddle, M. (1996) Terminal care of Non-Cancer Patients, *Clinics in Geriatric Medicine*, 12(2), pp. 349-358.

Wary, B (2003) Geriatrics and palliative care: the best of both worlds…*European Journal of Palliative care,* 10(2), pp.29-31.

World Health Organization (1990) *Technical report series 804,* Geneva, World Health Organisation.

Table 1

Table summarising the studies included in the review

Paper	Purpose	Sampling	Data Collection	Data Analysis	Ethical Issues	Major Findings
Michel et al 2002 Switzerland Review	Review of the literature on end of life care of persons with dementia	Search strategy and inclusion exclusion criteria not detailed	Not detailed	Not applicable	Not applicable	Dementia is a risk factor for early death No survival differences between Alzheimer's and Lewy body disease, although patients with vascular dementia have the worst prognosis Cardiac causes of death are significantly more frequent in vascular dementia than other types Ethical issues not close consideration Need for improvement in communication with both patients and carers

Sampson et al 2006 England Retrospective case note study	To compare difference of care received by patients with and without dementia, who died during acute hospital admission	Aged 70 years and over Patients who died whilst inpatient on an acute hospital ward between 1/4/2002-31/3/2003 Notes selected using random number tables	Data extracted from medical notes	Demographic information including age, gender, type & severity of dementia and religious faith Abbreviated Mental Test Scores (AMTS) Mini Mental State Examination (MMSE) End of life care assessed using Liverpool Care Pathway Statistical analysis performed using SPSS (version 11.0) Relationship between dementia status & dichotomous variables investigated using Fisher's exact test. Mann-Whitney U test was used for continuous variables	Ethical approval obtained via hospital ethics committee	Dementia patients have particular difficulty assessing palliative care services Older People with dementia receive significantly fewer palliative care medications Dementia Patients have less attention paid to the identification of spiritual needs and religious background
Lloyd-Williams et al 2002 England Retrospective Audit	To see if multidisciplinary guidelines improve the palliation of symptoms in the terminal phase of dementia	All deaths over 12 month period in a long stay psychiatric hospital Dates not provided	Data extracted from medication cards and case notes.	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 27 deaths included in the	Not identified	Multidisciplinary guidelines can improve palliative care.

				study		
Aminoff et al 2004 Israel Quantitive	To evaluate the level of suffering of end-stage dementia patients during their final hospital stay using the MSSE tool (Mini Suffering State Examination)	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	Level of suffering was evaluated weekly from admission by the MSSE by medical staff and the patients family	Demographic and clinical variables analysis of variance (ANOVA) Kruskal Wallis nonparametric 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.	Authorized by local ethics Helsinki Committee	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 minimize 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.

Ahronheim et al 1996 United States of America Quantitive	To compare the treatment and diagnostic interventions given to 2 groups of incurably ill, elderly patients in their last days of life- patients with advanced cancer and those with advanced dementia 2 hypothesis 1) That patients with advanced dementia are treated differently at the end of life from patients with advanced cancer. 2) To quantitate the use of life-prolonging and invasive diagnostic and therapeutic interventions in both groups of patients	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 1992-1993. Exclusion criteria identified	Retrospective review of hospital charts	Immediate cause of death was obtained from the patient's death certificate. Comparison of the patient characteristic variables was assessed using X2 analysis. Logistic regression was used to evaluate the impact of the diagnosis on the use of diagnostic tests	Not identified	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.

Ahronheim et al 2000 USA Randomized Controlled Trial and Descriptive Analysis Quantitive	To determine if a palliative care approach could be implemented for patients with advanced dementia and if this approach could enhance patient comfort.	Prospective, randomized controlled trial of palliative care versus usual care in a group of hospitalized acutely ill patients who had advanced nonreversible dementia.	Eligible patients admitted to acute hospital over a 3 year period. Patients were eligible if they had advanced dementia and been hospitalized for acute illness 99 patients met criteria over 3 year period. 48 randomly assigned to the intervention group. 51 to the control group	Advanced dementia assessed using Functional Assessment Staging Tool (FAST)	Ethics approval obtained	Study failed to demonstrate that a palliative care intervention by a team could have an impact on specific treatment plans in hospitalized 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 hospitalization so goals can be established when there is less urgency to make life and death decisions.

Evers et al 2002 USA Quantitive	To establish the frequency of palliative and aggressive treatment measures among patients with and without dementia during the last six months of life	All patients lived in chronic care facilities at time of death	Post-mortem chart review Antemortem data for 279 patients with dementia and 24 control patients Between 1985-2000 this was then divided into 3 cohorts.	Severity of dementia was defined by clinical dementia rating scale Chi square test were used to compare categorical variables.	Ethics approval obtained	Systematic antibiotics is 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.

Maguire et al 1996 Ireland Survey	To report the results of a survey of family members on their attitudes to disclosure of diagnosis of Alzheimers disease	100 consecutive family members accompanying patients with diagnosed Alzheimers disease.	Survey of 3 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 Alzheimers should it become available?	Not Identified	Not Identified	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
Hinkka et al 2002 Finland Questionaire Quantitive	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	Questionaire sent to: 300 surgeons 300 internists 500 GPs 82 Oncologists Response rate 62%	Postal Survey 1999	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	Not identified	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.

Volicer et al 2003 Retrospective survey Quantitive	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.	Retrospective survey of a nationwide sample of family caregivers of demented individuals who died during the year preceding the survey.	Questionaire 938 distributed questionnaires but only 27% response rate.	ADL's measured by the six-item Katz Index of Activities of Daily Living. 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	Ethics approval obtained	End of life experiences of individuals with dementia differ according to setting of care. Those who were cared for at home during the last 90 days had fewer symptoms than those cared for in other areas. Those who died at home had fewer signs of physical distress.
Campbell et al 2004 USA Quantitive	To compare usual care with a proactive case-finding approach for critically ill patients with terminal dementia using an inpatient palliative care service.	Retrospective chart review Patients with advanced-stage dementia admitted to ICU	26 patients included from 1999-2001	Functional assessment staging and national hospice organizational guidelines Age, gender, Acute Physiology and chronic health evaluation score (APACHE) Unpaired students t-test and Pearson chi-square were used when comparing variables between groups Statistical calculations – SPSS for windows	Ethical approval granted	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 use of nonbeneficial resources. Physicians are more comfortable

						with not adding life support and resuscitation but less confident about stopping interventions, symptom management and family grief support.
Lloyd-Williams 1996 England Audit	To determine the most prevalent symptoms in terminal dementia and to assess the palliation given.	Case notes of most recent 25 pts deaths with end stage dementia	Death certificate should contain dementia as a contributory cause of death Main symptoms recorded	Not identified	Not identified	Pain and dyspnoea were the most common symptoms. There is a need for education of both nursing and medical staff re principles of palliative care
Volicer et al 2001 USA Questionnaire Quantitive	To study three scales designed to measure outcomes of care of persons suffering from terminal dementia.	Questionnaire of family caregivers whose loved one died during the previous year Response rate only 27.3%	Via Questionnaire	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	Ethical approval granted	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.

McCarthy et al 1997 England Quantitive	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	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	Interviews 10 months after death of patient	Chi-square test was used to compare frequencies	Not identified	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 caner patients and rated GP assistance less highly. Dementia patients needed more help compared to cancer patients at home.
Keene et al 2001 England Quantitive	To investigate the last phase of dementia and the causes of death, comparing autopsy and death certificate.	11 year, longitudinal study of participants with dementia living at home with a carer. All lived in Oxfordshire, UK.	Comparison of autopsy and death certificates diagnosis.	Present Behaviour Examination (PBE) Mini Mental State Examination (MMSE)	Ethics approval granted	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.
Morrison et al 2000 USA Quantitive	To examine survival for patients with end-stage dementia following hospitalization for hip fracture or pneumonia and to compare their care with that of cognitively intact older adults	Patients 70 years and older hospitalized with hip fractures or pneumonia who had a diagnosis of dementia in a large New York hospital between 1996-1998	Hospital chart evaluation	X2 Analyses and t tests were used to compare patient characteristics and other variables. The Cox proportional hazards regression model was used to examine survival	Ethics approval granted	High 6 month mortality for patients with end-stage dementia following hospitalization for pneumonia (53%) or hip fracture (55%)
Roger 2006 Canada Review	Review of the literature on palliative care of those dying with dementia	Search strategy	NA	NA	NA	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

Engel et al 2006 USA Cross-sectional study	To identify factors associated with satisfaction with care for healthcare proxies of nursing home residents	13 Nursing homes in Boston. 148 residents aged 65 and over with advanced dementia and their formally designated healthcare proxies	Satisfaction With Care at the end of Life Scale	Descriptive and inferential statistics	Ethical approval obtained	Variables independently associated with greater satisfaction were: Discussion re advanced directives, greater resident comfort, care in a speicalised dementia unit and no tube feeding
Downs et al 2006 UK Theoretical paper	To discuss four models used to understand dementia: Neurological, neuro-psychiatric, normal ageing and person-centred approaches.	NA	NA	NA	NA	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'
Sampson et al 2006a UK Systematic review	To complete systematic review regarding the efficacy of a palliative care model for patients with dementia	Structured literature search using a full range of databases	30 articles identified, 4 eligible for full appraisal but only 2 met full criteria for inclusion	NA	Ethical issues concerning the ability to conduct ethically robust research studies	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.
Mitchell et al 2004 USA Retrospective cohort study	To describe and compare the end-of-life experiences of older people dying from advanced dementia in nursing home and home care settings	People over 65 who had died within 1 year of admission to nursing home (n=2730) and home care settings (n=290).	Minimum Data Set data used	NA	NA	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'.

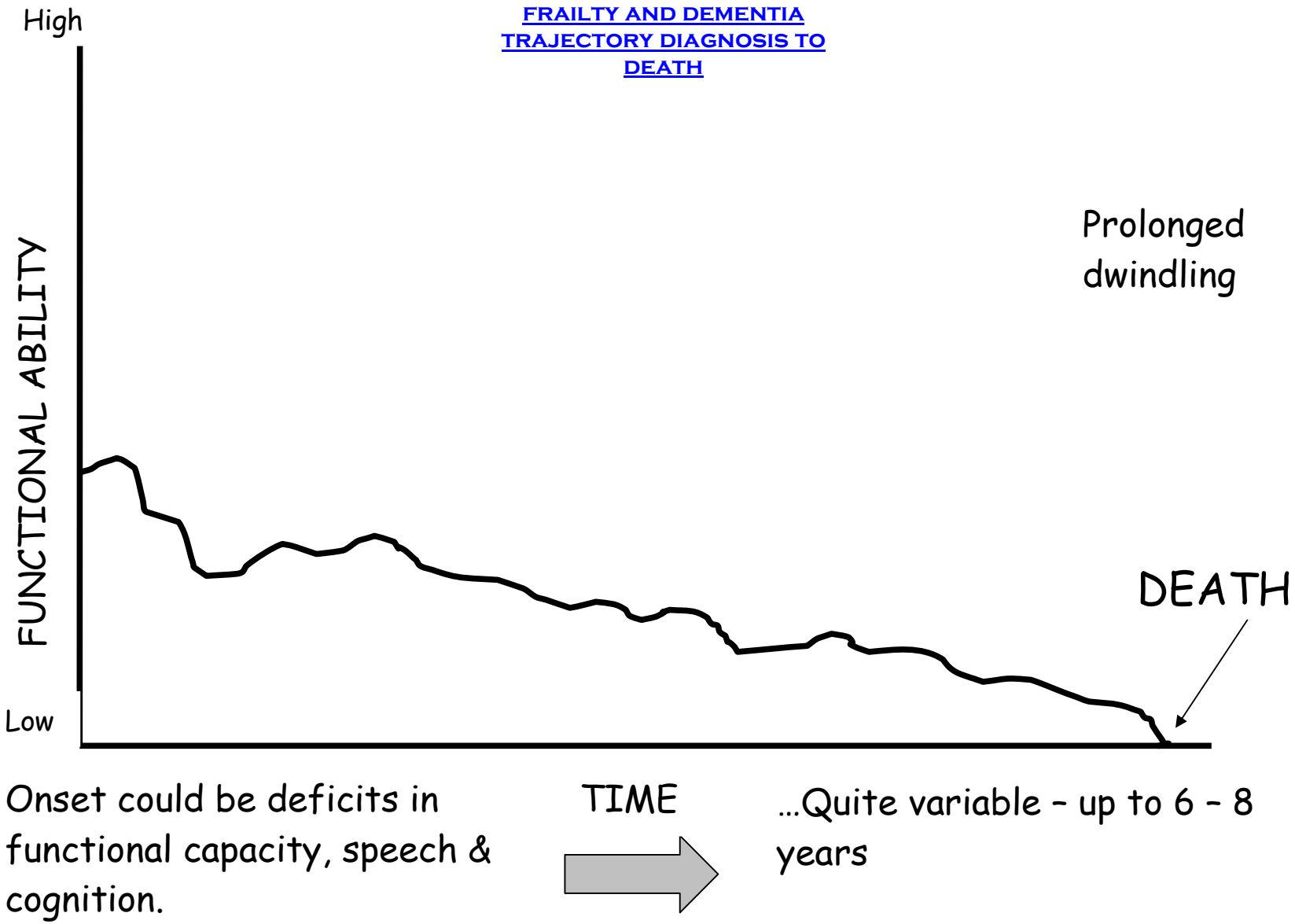
Sachs et al 2004 USA Theoretical paper	To discuss the challenges to providing high quality edn-of-life care for patients with dementia	NA	NA	NA	Discussed in the context of promoting high quality care	They comment on: the way in which dementia is still not considered by some as a terminal illness; decision making in advanced dementia treatments; symptom assessment and management; experiences of the caregiver; bereavement.
Aminoff and Adunsky 2006 Israel Cohort study	To study any relationship between Mini-Suffering State Examination (MSSE) scale and survival of end-stage dementia patients	Cohort study of 252 end-stage dementia patients with a 6 month follow-up	MSSE scores	Descriptive and inferential statistics	Approval obtained	Patients dying within 6 months were older. Low scoring MSSE patients had higher mean survival times. They concluded that use of MSSE scale helps to identify those end-stage dementia patients more likely to benefit from palliative care.

Mitchell et al 2004 USA Retrospective cohort study	To compare the end-of-life experiences of patients with advanced dementia and terminal cancer admitted to nursing homes in New York	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	Minimum Data Set	Descriptive and inferential statistics		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.
Forbes et al 2000 USA Focus group study	To examine the affective and cognitive decision making processes regarding end-of-life treatments for nursing home residents	Family members (n=28) participated (aged 41-85 yrs)	Focus Groups	Thematic qualitative data analysis		5 themes generated: emotional effect; insult-to-life story; two faces of death; values and goals regarding end-of-life treatment; and the unrecognized dying trajectory. They concluded that family members need support during

						this process.
Robinson et al 2005 UK Review	To review current knowledge around end-of-life care in dementia	NA	NA	NA	NA	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.
Rurup et al 2006 Netherlands Survey	To investigate the attitudes of physicians, nurses and relatives towards medical end-of-life decisions concerning patients with dementia	Physicians, nurses, relatives	15 statements about artificial feeding and hydration, advanced directives, hastening death, self-determination and euthanasia presented to the sample.	Thematic analysis		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

Albinsson and Strang 2002 Sweden Phenomenological interview studu	To investigate how staff caring for patients with dementia deal with life and death (existential) issues	31 carers, mostly unqualified nursing staff	Qualitative interviews	Phenomenological approach taken to analysis.	Approval granted by regional ethics committee	All participants found existential issues difficult to discuss with both patients and their family members. They make recommendations for improving end-of-life care.
Caron et al 2005 Canada Grounded theory qualitative study	To explore the experience of family care givers in making end-of-life decisions	24 care givers involved in the care decisions of an older family member with advanced dementia	Interviews	Constant comparative data analysis method	Ethical approval granted	They identified 5 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.

Figure 1


FRAILTY AND DEMENTIA TRAJECTORY DIAGNOSIS TO DEATH
High
FUNCTIONAL ABILITY
Low
Prolonged dwindling
DEATH
Onset could be deficits in functional capacity, speech & cognition.
TIME
…Quite variable – up to 6 – 8 years