

Palliative care for people with dementia

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The number of people with dementia will rise dramatically over the next 20 years. Currently, one in three people over the age of 65 will die with dementia. A PubMed search using MeSH headings for 'dementia' AND 'palliative care' and for specific areas, i.e. enteral feeding. National reports, UK guidelines and policies were also consulted. Advanced dementia is now being perceived as a 'terminal illness' with a similar symptom burden and prognosis to advanced cancer. People with dementia have poor access to good quality end-of-life care. Interventions such as antibiotics, fever management policies and enteral tube feeding remain in use despite little evidence that they improve quality of life or other outcomes. Research is required on the effectiveness of 'holistic' palliative care, outcome measures and the impact on carers and families.

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Introduction

Dementia is caused by progressive neurodegeneration, leading to impairment of memory, executive function, speech and language comprehension and ability in activities of daily living. As well as these cognitive impairments, most patients develop personality changes and behavioural and psychological symptoms of dementia (BPSD) such as depression, psychotic symptoms (hallucinations and delusions), wandering and purposeless activity and agitation or aggression. The dementias are caused by a range of underlying neuropathological processes, the commonest form being Alzheimer's disease (31%), followed by vascular dementia (22%), Lewy body disease (11%) and fronto-temporal lobar degeneration (7.8%).¹

Currently approximately 600 000 people in the UK have dementia (10% of those over the age of 65 years) but it is estimated that by 2026 this number will approach 840 000 rising to 1.2 million by 2050.² Worldwide prevalence figures are also set to rise steeply; currently an estimated 24.3 million people worldwide have dementia but the number affected will double every 20 years to 81.1million in 2040.³ Thus, increasing numbers of people will die whilst suffering

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from dementia. Estimates from the UK MRC-CFAS project, a large multicentre study looking at the health and cognitive function of 13 000 older people, suggest that people who died between the ages of 65 and 69 years had a 6% risk of dying with dementia, rising to a 58% risk of dying with dementia in those over 95 years. In the UK, one in three people over the age of 65 will die whilst suffering from dementia.⁴ The recent English National Dementia Strategy has rightly focused on early detection and treatment of dementia with cholinesterase inhibitors or psychological and social interventions. However, there is no evidence that such interventions prolong life in people with dementia and there has been recent interest in how a palliative care approach may be beneficial for people with advanced dementia.

The World Health Organization defines palliative care as:

The active, total care of patients whose disease is not responsive to curative treatment. Control of pain, of other symptoms, and of psychological, social and spiritual problems is paramount. The goal of palliative care is achievement of the best quality of life for patients and their families.

Methods

For this review a PubMed search using the Medical Subject Headings (MeSH) 'dementia' AND 'palliative care' was conducted. This yielded 199 relevant articles (years 1985 till date). Of these 46 articles were reviews. The most common topic areas were legal and ethical discussion (21 papers), the use of antibiotics and 'fever management strategies' (12 papers), enteral tube feeding (11 papers), advance care planning and proxy decision making (10 papers), symptoms experienced at the end of life (nine papers) and staff education programmes (9 papers). It is of note that there were only six papers on outcome measurement and four papers describing interventions and care programmes. Other searches were undertaken for specific areas relevant to the field, for example enteral tube feeding and prognosis in dementia.

Is dementia a 'terminal' illness?

Even a minor level of cognitive impairment is a strong independent predictor of mortality in older people, even after other health and social factors have been controlled for.⁵ A systematic review has demonstrated that people with dementia have significantly increased mortality risk over two and a half times that of those without (pooled odds ratio: 2.63, 95% CI: 2.17–3.21).⁶ A recent UK population study gave a

median survival time from diagnosis of 4.1 years;⁷ this is strongly influenced by age with those aged 65–69 years surviving for a median of 10.7 years, and those aged 90 years and above surviving for 3.8 years.⁷

Only one-third of people with dementia ever receive a formal diagnosis.⁸ This will often occur at a time of transition when moving into a residential or nursing homes or crisis, for example on acute hospital admission. The median length of stay in UK nursing homes, where the majority of residents will have moderate or severe dementia, is 18 months. With a median survival time of 1.3 years, advanced dementia is associated with a life expectancy similar to that of well-recognized terminal diseases such as metastatic breast cancer.⁹

The combination of dementia and acute hospital admission is particularly malignant; patients with advanced dementia have markedly increased 6-month mortality after hip fracture (55%) or pneumonia (53%) compared with 12 and 13% in cognitively intact patients.¹⁰ Shorter term mortality is also very poor with 24% of those with moderate or severe dementia dying after acute unplanned medical admissions compared with 7.5% of those who did not have dementia.¹¹ These data suggest that acute physical illness, requiring emergency hospital admission, such as pneumonia or urinary tract infection may be indicator of imminent death in people with advanced dementia.^{9–11} Medical and nursing home staff consistently overestimate prognosis in advanced dementia; at nursing home admission only 1.1% of residents were perceived to have life expectancy of less than 6 months; however, 71% died within that period.¹²

The symptom burden of advanced dementia

Patients with advanced dementia suffer a range of symptoms, similar to those found in the terminal stages of cancer, for example, pain and dyspnoea. Pressure sores, agitation and eating problems (i.e. difficulty swallowing or loss of appetite) are very common (see Table 1).

A retrospective study comparing symptoms experienced in the last year of life by 170 people with dementia compared with 1513 cancer patients showed that the symptom burden between the two groups was comparable; in particular 64% of dementia patients, experienced pain and 57% loss of appetite. The health-care needs of both groups were also similar.¹³

Pain

Pain is common in people with advanced dementia and is often under-detected and under-treated.¹⁴ Retrospective interviews with relatives

Table 1 Prevalence of symptoms in nursing home residents with advanced dementia.

	Mitchell <i>et al.</i> ⁹	DiGiulio <i>et al.</i> ⁶⁰	Aminoff and Adunsky ⁶¹
Study details	Proportion of patients with symptoms 18 months prior to death (prospective study), <i>n</i> = 323	Proportion of patients in the last 30 days of life (retrospective study), <i>n</i> = 141	Proportion of patients in the last week of life (prospective study), <i>n</i> = 71
Dyspnoea	46	39	–
Pain	40	26	18
Pressure ulcers	39	47	70
Agitation /restlessness	54	20	72
Aspiration	41	–	–
Eating problems	86	–	95

Values given are represented in percentages.

and carers indicate that significantly more dementia patients are reported to experience pain in the last 6 months of life compared with those with cancer (75% versus 60%)¹³ but pain control is often inadequate. In patients with fractured neck of femur, those with cognitive impairment were prescribed a third as much analgesia as cognitively intact controls.¹⁵ There is no consistent evidence to suggest that pain experience is less intense, but people with advanced dementia will have difficulties in communicating that they are in pain and this often manifests as behavioural change such as agitation, distress, social withdrawal or resistive behaviour.¹⁴

The ‘gold standard’ for pain assessment is self-reporting. Despite widely held beliefs to the contrary, many patients with moderate to severe dementia can report pain reliably.¹⁶ In those with communication difficulties it may be necessary to use direct observation or validated observational pain scales such as the Abbey Tool.¹⁷ The assessment of pain in advanced dementia is, however, complex and it has been suggested that there is no evidence that pain produces any particular signs or behaviours that are unique to pain;¹⁸ these may be the result of other forms of distress and thus tools such as the Disability Distress Assessment Tool may be more appropriate.¹⁹

Eating and swallowing

People with advanced dementia often develop swallowing difficulties. Two methods of enteral tube feeding are used: a nasogastric tube (a tube that is passed through the nose and into the stomach) or via a percutaneous endoscopic gastrostomy (PEG). There have been no randomized controlled trials of these interventions in people with advanced

dementia. A recent Cochrane Review²⁰ found inconclusive evidence that enteral tube feeding provides any benefit in dementia patients in terms of survival time, mortality risk, nutritional parameters and improvement or reduced incidence of pressure ulcers. There have been no studies on the effect of these interventions on quality of life. Enteral tube feeding may increase pulmonary secretions, incontinence, mortality and morbidity. PEG is an invasive surgical procedure with significant postoperative risks including aspiration pneumonia, oesophageal perforation, migration of the tube, haemorrhage and wound infection. The decision to use enteral tube feeding is emotive and influenced by complex ethical issues, clinical need, local practice, physician and carer preference and whether there is an advance directive or advance care plan in place. Clinicians may feel pressurized by institutional,²¹ societal or local laws to intervene. For example, in the USA, Illinois requires a physician to seek a court order to withhold or withdraw tube feedings but no other states do. Ethical considerations include whether life in advanced dementia should be artificially prolonged and what is considered to constitute 'euthanasia', i.e. that by withholding food and fluids death will be hastened. It has been argued that the absence of evidence demonstrating a benefit of tube feeding does not mean that it is inappropriate in all patients with advanced dementia and that each individual deserves a holistic assessment by a specialist in swallowing; all appropriate interventions should be considered including the option of a gastrostomy.²² Some ethicists suggest that artificial nutrition and hydration are medical treatments that can legitimately be withheld if their risks, *judged according to the patient's values*, outweigh their benefits;²³ however, this implies values are known or documented and this is often not the case.

Behavioural and psychological symptoms of dementia

BPSD are common, affecting 90% of people at some time during the course of their illness. They are both extremely distressing for the person with dementia and their family and carers and a strong predictor of institutionalization to nursing or residential homes.²⁴ Different BPSD tend to emerge at different stages of the illness, for example, mood disorders and depression are noted earlier in the disease course and psychotic symptoms (hallucinations and delusions), more common in the moderate stages. Wandering and agitation tend to be the most enduring BPSD. In the advanced stages of dementia over half of patients remain agitated and distressed.⁹ The management of these symptoms is complex and requires a structured approach, using a range of therapeutic approaches. Difficult behaviours such as aggression and

resistiveness to care may be indicators of unmet needs such as under-detected or under-treated pain, delirium or infection. Patients therefore require a full assessment and this can be challenging in advanced dementia when verbal communication is limited. Basic aspects of personal care such as providing glasses or hearing aids should be considered first. Environmental modifications such as limiting noise or providing outside space or gardens where people can walk can reduce agitation. Dementia care mapping is based on the work of Kitwood²⁵ and the philosophy of ‘person-centred care’, which aims to promote a holistic approach. Kitwood has defined the psychological needs of people with dementia as comfort, occupation, inclusion, identity and attachment; all of key importance at the end of life. A trained observer assesses people with dementia continuously over representative time periods and makes detailed notes on the care received. Activities are quantified under-structured headings. More general judgements are also made including measures of ‘ill being/well being’. The data are analysed and interpreted and can then be used to improve care. The technique is well established and validated and has been used in a variety of settings including nursing homes.

Psychological interventions for example simple ‘ABC’ analysis (documentation of the Antecedents of the behaviour, the Behavioural disturbance and the Consequences of the behaviour) can reveal patterns and triggers for a particular problem, and are also very effective^{26,27} and drugs should be used as a last resort. Antipsychotic medications both typical and atypical can cause parkinsonism, prolongation of the QT interval and increase the risk of stroke and death.²⁸

Infections

Pneumonia and other infections, especially urinary tract are common in advanced dementia. Over 18 months, 53% of nursing home residents with advanced dementia will have a febrile episode, and 41% will have pneumonia.⁹ These will be the immediate cause of death in up to 71% of cases.²⁹ People with advanced dementia are often immobile, bed bound, at increased risk of aspiration and may have impaired immunological function. The use of antibiotics to treat fevers and recurrent infections is one of the most controversial issues in this field. Fabiszewski *et al.*,³⁰ demonstrated no difference in mortality between people receiving antibiotics and those receiving only ‘palliative’ care. In a cohort of Dutch nursing home patients, van der Steen *et al.*³¹ found that patients treated with antibiotics survived for longer (27% died compared with 90% of those who did not have antibiotics); however, this may have been related to the fact that antibiotics were

withheld from patients whom physicians believed had more severe dementia. Some research has suggested that withholding antibiotics increases the level of discomfort³² but it has also been argued that antibiotics might delay death leaving the patient exposed to the risk of further pain and suffering and prolonging the dying phase. In this situation, adequate symptomatic control through the use of analgesia may be more appropriate.

Legal and ethical considerations

A detailed discussion is beyond the scope of this review but the reader is recommended to consult the recent Nuffield Foundation Bioethics review on dementia, which contains extensive consideration of these issues.³³

Advance care planning

Advance care planning (ACP) is understood in a variety of different ways; the term is often used without definition or explanation. Advance care planning usually involves a process of discussing and recording priorities and wishes for future care and treatment between the person and health and/or social-care providers. It attempts to anticipate the future deterioration of a person's condition so that when a person is no longer able to communicate, wishes and preferences can be met.³⁴ The discussion and process of formulating an advance care plan may actually be more valued than the final document that is produced.

In the UK, the Mental Capacity Act (2005) provides a legal framework for this process. The UK Mental Capacity Act (2005) gives competent adults in England and Wales the legal right to refuse treatment (i.e. artificial feeding and nutrition, cardiopulmonary resuscitation) through the writing of an 'advance decision'. People can also make an 'advance statement', which reflects their general beliefs and personal values about the sort of care they would like to receive in the future, for example they can express the wish to die at home and not in hospital.

Lasting Powers of Attorney were also introduced through the UK 2005 Mental Capacity Act and enable the appointment of an attorney to make proxy decisions when the person with dementia no longer has the capacity to do so. A 'Personal Welfare' Lasting Power of attorney allows the attorney to give or refuse consent to medical treatment, if such preferences have been expressed in the document. Similar

frameworks are available in other countries to facilitate advance care decisions, for example the 'Let Me Decide' programme from Australia has led to a significant decrease in the transfer of nursing home residents to acute hospital with no changes in overall mortality.³⁵

In contrast to those with cancer and other advanced chronic disease, most people with severe dementia will have profound cognitive impairment and will lack the capacity required to make decisions about their care and treatment. People with dementia are significantly less likely to have an ACP compared with those with cancer, although uptake of the process in cancer remains variable.¹² Ideally, ACP should be attempted in the earlier stages of dementia when a person is still competent to make decisions and express their values and preferences. In current UK clinical practice, it still remains rare for a person with advance dementia to have an advance care plan.

Current issues in management

Inappropriate interventions and treatment at the end of life

Despite the high mortality in advanced dementia, particularly for those who are admitted to the acute hospital, people with dementia receive as many painful investigations and procedures (for example, arterial blood gas sampling) and are more likely to be physically restrained compared with patients who are cognitively intact.¹⁰ This suggests that clinicians fail to adopt a palliative or supportive approach to patient care, possibly because people with advanced dementia are not perceived to be suffering from a 'terminal illness'. This may be due to poor understanding of the pathophysiology of dementia amongst health-care professionals.³⁶ Other vital components of good end of life and person-centred care are also neglected with little acknowledgement of spiritual needs, withdrawal of inappropriate medications or referral to hospital palliative care teams.³⁷ Patients dying with dementia in nursing homes often receive burdensome interventions. In the American study of Mitchell *et al.*⁹ 29% received enteral tube nutrition and 12.4% were hospitalized.

Supporting carers and relatives

There has been little research on carers of people with advanced dementia and their experiences of caring at the end of life. Carers and family members of people with dementia often suffer from significant levels of distress and burden. The long and unpredictable nature of

disease progression and BPSD add to this. Carers and families are described as experiencing ‘anticipatory’ or ‘pre-death’ grief; the cognitive deterioration of dementia leads to the loss of personhood often long before actual bodily death.³⁸ This grief is distinct from depression and may be related to the quality of care that the person with dementia received. Because people with advanced or end-stage dementia are likely to lack the capacity to make decisions, carers are frequently expected to act as ‘proxies’. They may have to make difficult and emotionally demanding choices, for example, regarding gastrostomy insertion or resuscitation. Educating the carers of people with dementia about the clinical features and implications of advanced disease increases the likelihood that they will choose ‘comfort care’ for their relative rather than aggressive medical interventions. When health-care proxies are aware of poor prognosis and the risk of clinical complications, their relatives with dementia are less likely to receive burdensome interventions at the end of life.³⁹

Access to hospices

It is often stated that people with dementia are ‘denied’ access to hospices; less than 1% of hospice patients in Europe have a neurological diagnosis⁴⁰ and in the USA, less than 7% of hospice patients have primary diagnosis of dementia.⁴¹ The reasons for this are complex and related to many of the issues described above, for example the fact that dementia is not perceived to be a terminal illness and concerns that hospice staff will not be able to manage BPSD.^{42,43} Patients with dementia are also less likely to be referred to palliative care services and in many health systems access to hospices is dependent on recommendations from these services. It has been argued that hospices provide ‘specialist’ palliative care and that they should rightly focus on cases of complex need—most of the symptoms experienced by people with dementia at the end of life such as pain or difficulties in swallowing do not require specialist intervention but good generalist care.

Improving palliative care for people with dementia

The evidence base is somewhat limited, particularly when compared with research on palliative care for people dying from cancer. Systematic reviews have identified how care mainly focuses on specific interventions such as ‘fever management policies’, pain control or the withdrawal of care, i.e. *not* prescribing antibiotics, rather than a more active palliative model.^{44,45} Good person-centred care requires a more

rounded approach and a number of ‘multicomponent’ complex interventions and pathways have been developed that may improve the quality and outcomes of care for older people with dementia in the acute hospital and in the community.

Care pathways and policies

The English National Dementia Strategy⁸ contained little regarding end-of-life care and the English End of Life Care Strategy⁴⁶ made little specific reference to dementia; perhaps this illustrates and reflects how patients with dementia fall through gaps in the health and social-care system? The National Institute for Clinical Excellence guidelines for dementia do include some recommendations, in particular the use of the Gold Standards Framework and the Liverpool Care Pathway for the care of the dying.

The gold standards framework

The UK ‘Gold Standards Framework’ (GSF) is a multidimensional programme that supports and trains staff to identify patients requiring palliative or supportive care towards the end of life. It uses a structured approach to recognize when the last year of life may have begun, to assess patients’ needs, symptoms and preferences and to plan care around these, in particular supporting people to live and die where they choose. Although not developed specifically for patients with dementia, the GSF developed for care homes attempts to enhance communication between GPs and other specialists, particularly out of hours care. Tailored individual advance care plans are developed for residents and these have been shown to reduce acute hospital admission and hospital deaths by at least 50%.⁴⁷

The liverpool care pathway

The Liverpool Care Pathway was originally developed to improve care in hospital for cancer patients during the last 48 h of life.⁴⁸ It has been modified for use in people dying with other diagnoses and different settings including hospices and nursing homes. The pathway has three phases: initial assessment of the patient, ongoing assessment and care after death. As well as attending to medical needs such as the discontinuation of inappropriate interventions and medications and the provision of comfort measures for example, mouth care, the pathway enhances person-centred care by assessing the patients’ insight into their situation, their psychological and spiritual needs and those of their family. There are, however, a number of issues pertinent to people with dementia that may challenge implementation for these patients. The pathway is only of use if it is

recognized that a patient is moving into the ‘dying phase’ and this can be difficult to identify in people with advanced dementia. Concerns have been raised that in dementia ‘dying’ can take many years and that food and fluids may be withdrawn too early.⁴⁹ However, the pathway is flexible and it is entirely appropriate that patients are sometimes moved from the pathway back to more ‘active’ management should their clinical condition improve. Future adaptation and evaluation of the pathway for use in people with dementia would significantly enhance quality of care.

Complex interventions and care programmes

Interventions in hospital settings

Ahronheim *et al.*⁵⁰ conducted a randomized controlled trial of an intervention in which people with dementia received assessment and care plan recommendations from a palliative care team with the goal of enhancing patient comfort in an acute hospital. The intervention did not decrease rates of re-admission to hospital, average length of stay or mortality, but there was a significant increase in written palliative care plans and patients received fewer intravenous drugs. The authors highlighted the ‘unique barriers’ to providing good end-of-life care, including prognostic uncertainty, and suggest that care planning may be more effective when done outside the busy acute hospital environment.

Lloyd-Williams *et al.*⁵¹ used multi-disciplinary prescribing guidelines on wards for older people with dementia. There was a significant decrease in the prescribing of antibiotics in the last 2 weeks of life and patients were much more likely to be prescribed analgesia, including opiates.

Interventions in nursing homes and specialist care units

A specific approach in North America has been that of the ‘Dementia Special Care Unit’ (DSCU). Volicer *et al.*⁵² compared this approach with nursing home settings and found that the DSCU, which provided a palliative care approach focusing on ‘maintenance of patient’s comfort rather than on maximal survival’, led to less discomfort, fewer antibiotic prescriptions, intravenous drugs and decreased transfers to the acute hospital. Mortality in the DSCU was higher but costs significantly lower.

Training and educational programmes on end-of-life care for nursing home staff also appear to be effective in improving knowledge and increasing satisfaction with end-of-life care in bereaved family members.⁵³

Interventions in the community

The Palliative Excellence in Alzheimer Care Effort Programme is an American programme set up to improve end-of-life care for people with dementia. It takes a long-term disease management model,

integrating ‘palliative care into ongoing comprehensive primary care of persons with dementia over the disease course, from initial diagnosis to death’.⁵⁴ The patient-centred principles of the programme include advance care planning, education on the disease process, improved care co-ordination and family support. This is implemented by clinical nurse specialists who coordinate care between families, physicians and other health and social-care professionals. Those involved in the programme were more likely to die in a hospice or a place of their choosing, less likely to die in the acute hospital and their carers were more satisfied with the quality of care received.

In the UK the ‘Hope for Home’ service has supported patients with severe dementia and their families, providing a multi-disciplinary and holistic model coordinated by a specialist in old-age psychiatry. Preliminary results have shown that total cost savings of home care compared with nursing home care for 14 patients was £696 930 and that 57% of participants died in their own home⁵⁵—a significantly higher proportion than would be expected in the UK general population (22%).⁵⁶

Research on end-of-life care for people with dementia

Searching the literature on this field reveals a lack of empirical research. There are a number of barriers to conducting good quality research in this field. There is no consensus on what defines severe or ‘end-stage’ dementia. Much of the work on prognosis originates from the USA where there is a focus on determining ‘hospice appropriateness’, the point at which a person has an estimated lifespan of 6 months and is entitled to hospice care. These guidelines are better at predicting who *will not* die within 6 months than those who will. Prognostic tools are not well tested and are only valid for specific populations.⁵⁷

There are complex ethical issues around research in this field. People with advanced dementia will be unable to give informed consent to participate and, may not have relatives who can give assent to their participation. Conducting randomized controlled trials of palliative care interventions is challenging because complex methodologies such as cluster randomization of hospital wards or nursing homes are often required.

Conclusions

The numbers of people with dementia who will need end-of-life care is set to increase rapidly over the next 10 years. Charities and voluntary organizations have a growing interest in policy and provision in this

field, for example, in the UK the National Council for Palliative Care has set up a specific dementia project (see Box 1) and Marie Curie Cancer Care has widened its remit to include those with neurodegenerative disease such as dementia.⁵⁸

In terms of research, work is required to define clinically meaningful outcome tools. Measures of suffering and quality of end-of-life care need to be tested in a range of settings and populations.⁵⁹ We need to better identify people with advanced dementia who are nearing the end of life so they and their carers can benefit from palliative care.

Box 1 Useful resources.

Preferred Priorities for Care (PPC): <http://www.endoflifecare.nhs.uk/eolc/ppc.htm>.

Gold Standards Framework: <http://www.goldstandardsframework.nhs.uk/>.

Liverpool Care Pathway: <http://www.endoflifecare.nhs.uk/eolc/lcp.htm>.

National Council for Palliative Care: <http://www.ncpc.org.uk>, <http://www.ncpc.org.uk/policy/dementia.html>.

Dementia UK: <http://www.dementiauk.org>.

Alzheimer's Society: <http://www.alzheimers.org.uk/>.

Admiral Nursing *DIRECT*: 0845 257 9406. Telephone information and support line for family carers, people with dementia and professionals. direct@dementiauk.org.

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