Extending palliative care to patients with dementia

Palliative care should be available to all with a life-limiting illness, including those with dementia. This article examines the palliative needs of those with dementia and how these needs might be met.

The hospice movement was initially developed in response to the perceived needs of terminally ill cancer patients (Addington-Hall and Higginson, 2005). It is now a key principle in the guidance on the commissioning of palliative care services for adults that every person with any life-threatening illness has the right to receive appropriate palliative care. This has been endorsed by the National Institute for Health and Clinical Excellence (2006) and the National Council for Palliative Care (Evers et al, 2006), Lord Darzi's NHS next stage review and by the End of Life Care Strategy for England published by the Department of Health (2008a,b). Turning these strategies into a reality for all patients remains a challenge for all heath-care professionals. This article focuses on the particular challenges faced in providing palliative care for patients with end-stage dementia.

Dementia currently affects approximately 37 million people worldwide, with an estimated 775 000 cases in the UK (Evers et al, 2006). It affects 5% of those over 65 years of age and 20% of those over 80 years of age (World Health Organization, 1992). The number of those with dementia is expected to rise with an ageing population, with cases in the UK predicted to rise to 1.7 million by 2051 (Knapp and Prince, 2007). Dementia is a chronic progressive condition where there is a disturbance of multiple higher cortical functions including memory, orientation, comprehension, language and judgment. Impairments of cognitive function are commonly accompanied by a deterioration in emotional control, social behaviour and motivation (World Health Organization, 1992). A cohort study described median survival from estimated onset of dementia to be 4.6 years for women and 4.1 years for men (Xie et al, 2008).

Progressive dementia is an incurable illness and, until recently, was viewed as a 'living death' about which little could be done other than custodial care (Downs and Bowers, 2008). The recognition that the principles of palliative care should apply to patients with dementia has challenged this perception (Addington-Hall and Higginson, 2005; Hughes et al, 2005). Palliative care is defined by the World Health Organization (1990) 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 to achieve the best quality of life for patients and their families. Patients with dementia may have palliative needs that arise throughout the illness, but this article focuses more specifically on the palliative issues that may arise during the final stages of dementia.

There is a wide variation in the course of dementia among individual patients, but as disease progresses, there are signs and symptoms that may herald the final stages of dementia. There is a progressive worsening of memory, with increasing confusion and disorientation. Behavioural changes are seen in addition to a deterioration of speech. There is also a loss of mobility, with the patient becoming bed-bound and totally dependant. Appetite and ability to swallow are lost and hence aspiration becomes a risk. As a consequence of these neurocognitive, functional and nutritional deficits, bladder and bowel incontinence develop, infections become common and decubitus ulcers may also occur (Shuster, 2000; Davies and Higginson, 2004; Hughes et al, 2007).

Retrospective surveys of carers of people dying from cancer or dementia carried out by McCarthy et al (1997) demonstrated that dementia patients suffered from multiple symptoms in the last year of life; most common were mental confusion, urinary incontinence, pain, low mood, constipation and loss of appetite. Similar frequencies were reported for cancer patients, but dementia patients experienced these symptoms for a longer period of time. Dementia patients saw their GPs less often than cancer patients and the levels of assistance needed at home were greater for dementia patients.

There is clearly a role for palliative care surrounding symptom relief but other aspects of end-stage dementia care may also benefit from palliative input. As the disease progresses and more functions are lost, decisions have to be made regarding levels of medical intervention. This may involve discussion around feeding difficulties or whether to treat recurrent infections. Enabling decisions to be made regarding future care in advance is particularly challenging for patients with dementia. Assessing symptoms, such as pain, may be particularly difficult in advanced dementia where communication may be impaired. Providing psychological, social and spiritual

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care, an essential part of palliative care, is also important in dementia care, as is supporting the families of those with dementia. Finally providing good quality end-of-life care, wherever that may need to take place, is an important challenge for all those involved in dementia care. Each of these issues will be considered in turn, before finally considering how services may adapt and develop in the future to meet the needs of those with dementia.

Feeding difficulties

As dementia progresses, a large proportion of patients will develop feeding difficulties, with up to 93% of those with advanced dementia having some degree of dysphagia (Feinberg et al, 1992). These feeding difficulties can lead to aspiration pneumonia, weight loss and malnutrition, with subsequent inability to fight off infection. As with many other conditions resulting in dysphagia, percutaneous endoscopic gastrostomy feeding can be considered to provide nutritional support (Sanders et al, 2000). There is little evidence, however, that tube feeding prevents aspiration pneumonia in those with severe dementia as aspiration of oral secretions or regurgitated gastric contents is not necessarily avoided (Finucane et al, 1999).

Tube placement itself can cause death with perioperative mortality rates of between 6 and 24% and a poorer prognosis for those with dementia who have percutaneous endoscopic gastrostomy placement compared to other age-matched groups (Sanders et al, 2000). For patients with dementia referred for percutaneous endoscopic gastrostomy tube placement, survival rates are similar irrespective of whether they underwent the procedure or not (Murphy and Lipman, 2003). It is possible that, by the time many of those with severe dementia are referred for tube placement, they are already malnourished (Gillette-Guyonnet et al, 2007). This may therefore put them at a greater operative risk and make them less likely to gain survival benefit from tube placement.

Treatment of recurrent infections

Recurrent infections occur in those with dementia for a variety of reasons. Incontinence and urinary retention may lead to an increased risk of urinary tract infections. There is an increased risk of developing pneumonia caused by swallowing difficulties and decreased mobility. Other infections may also develop such as infected pressure ulcers caused by impaired ambulation (Shuster, 2000).

The issue of when to continue to treat pneumonia in those with severe dementia is controversial. Bronchopneumonia is the commonest cause of death for those with Alzheimer's disease (Burns et al, 1990) so it could be argued that the development of pneumonia could be a terminal event. Work carried out in the US comparing pneumonia patients with end-stage dementia to cognitively intact patients demonstrated that three times as many of the dementia group had died within 6 months of admission compared with the cognitively intact group (Morrison and Siu, 2000). However, antibiotics may provide some symptomatic benefit. Research carried out among nursing home residents with dementia demonstrated higher levels of discomfort in those who did not have their pneumonia treated with antibiotics (Van der Steen et al, 2002). Although there can be difficult decisions to make regarding the treatment of infections in those with end-stage dementia, careful discussion to weigh up the benefits and burdens of any treatment is always important.

Advance care planning

There are several very difficult treatment decisions that often have to be made during the course of a patient's illness. Distress can occur surrounding these decisions because of the long course of the illness, the patient's reduced capacity to take part in decision making, stress of the caregivers and underestimation of the terminal nature of advanced dementia (Shuster, 2000). The treatment decisions that may need to be made all involve balancing benefits and burdens to the person and therefore all need to be made for the individual. Advance care planning is a patient-centred and patient-driven dialogue with care professionals that can enable effective care to be delivered. Patients' comments can be recorded in a document such as the Preferred Priorities for Care and may include areas such as the importance of treatments to reduce and alleviate distress if and when this occurs, artificial feeding and management of repeated infections and wishes about future care in the last year of life. If, however, the patient has lost the capacity to make decisions about future care, decisions about future care will be made in the patient's best interests, advised by the patient's previous wishes, advance decisions to refuse treatment or lasting powers of attorney.

Research evaluating advance care planning in nursing homes has demonstrated a decrease in hospital admissions and some improvement in mortality of nursing home residents compared with homes without advance care planning programmes (Caplan et al, 2006). Early discussion of diagnosis could enable those with dementia to express their wishes when mentally capable (Robinson et al, 2005), thus allowing more person-centred care to be delivered in the terminal stages.

Symptom management

Most of the work surrounding symptom management in those with advanced dementia has focussed on pain management. A wide spectrum of symptoms may occur, the assessment of any symptoms in patients can be challenging because of difficulties with communication. In the field of pain management, numerous assessment tools have been developed which use behavioural cues to identify pain. The development of these tools has been in part driven by awareness that pain is often under-recognized

and under-treated in elderly patients (Fox et al, 1999). As patients with dementia are often unable to communicate their needs, there are concerns that pain is often ignored or pain behaviour ascribed to that person's dementia.

Reviews of pain behaviour assessment tools have concluded that there is no single recommended tool for use across populations and settings (Herr et al, 2006; Hadjistavropoulos et al, 2007). Concerns were raised by these reviews that as there is no evidence for any behaviour that solely indicates pain, using such tools could lead to an over-diagnosis of pain when the behaviour has a different cause. This finding was borne out by a study by Jordan (2008) using one such behavioural assessment tool, PAINAD (Pain Assessment in Advanced Dementia), to observe patients with severe dementia at various points in their day. Although half of the patients observed scored significantly on the PAINAD scale, only a third of those with significant scores were felt to be in pain. In addition, it is recognized that many patients may display unique ways of behaving when in pain; this is not adequately captured using a list of common pain behaviours, leading to important behaviours being overlooked.

It has been suggested that rather than attempting to identify a specific cause of distress such as pain, identifying global distress is the only possible starting point in those with severe communication difficulties (Regnard et al, 2007). The use of the carers' knowledge of the person has been highlighted as a method of identifying such distress. Once distress has been recognized, then the cause of the distress should be sought. These principles are used in the Disability Distress Assessment Tool (DisDAT) which has been used to assess pain in patients with severe dementia. The study carried out by Jordan (2008) demonstrated that much of the pain identified in those with severe dementia was musculoskeletal in origin and could be managed using simple non-pharmacological and pharmacological techniques. Many patients who had pain were already prescribed analgesics. Regular review of dementia patients' symptoms may therefore be required to ensure that worsening symptoms are not ignored.

Family support

Caring for someone with advanced dementia can be emotionally and physically exhausting. Often marked stress is caused by a diminishing capacity to participate in relationships as the carers lose the person they knew (Shuster, 2000; Davies and Higginson, 2004). This stress may be exacerbated if the dementia produces difficult behavioural symptoms. As a patient deteriorates, nursing home placement may become necessary. This can induce feelings of guilt and ambivalence. Once the person with dementia dies, their caregivers may need bereavement support, particularly if the grief is complicated.

A lack of information about the natural course of the disease can make it difficult for families to anticipate future events, hence families may insist on hospital admission for acute illnesses in their relative with dementia. Supportive care for families needs to be specifically designed based on the trajectory and nature of dementia. Admiral Nurses are specialist dementia nurses who work mainly with family carers providing practical advice and emotional support. Unfortunately their services are not available country wide (Robinson et al, 2005), therefore support for families must be provided from other sources, both professional and voluntary.

Psychological, social and spiritual needs

Behavioural symptoms such as aggression, delusions, wandering, agitation and sleep disturbance are common in dementia, with over 90% of patients experiencing 'behaviour disturbance' (Ballard and O'Brien, 1999). These non-cognitive symptoms seen in dementia are often described under the umbrella term of behavioural and psychological symptoms of dementia. Many of these symptoms form a syndrome that occurs after the onset of symptoms of dementia and varies over time (Burns and Winblad, 2006). Evidence suggests that these symptoms are important determinants of patients' distress, quality of life, carer burden and outcome in dementia. The symptoms are also important in leading to prescription of psychotropic drugs and nursing home placement (Ballard and O'Brien, 1999).

Multiple factors cause these symptoms, including the underlying brain disease, host factors and the environment. Thorough investigation of all the contributing dimensions is required in order to plan logical intervention (McKeith and Cummings, 2005), with treatment designed to address the underlying cause where possible. Non-pharmacological interventions can be helpful, including behavioural therapies, exercise, music therapy and changes to the care environment. Providing quiet spaces and privacy within a home has been shown to reduce negative behaviours. Antipsychotics, mood stabilizers, antidepressants and anxiolytics are commonly prescribed for patients with dementia to address some of these symptoms, but there have been few clinical trials to support the use of these drugs in this patient group. The evidence supporting the effectiveness of these drugs when managing behavioural and psychological symptoms of dementia is limited (McKeith and Cummings, 2005), although advising against them completely creates problems when managing those with severe behavioural disorders.

The provision of good quality care, including palliative care, should be delivered wherever those with dementia live. The proportion of those in residing in care homes increases as the condition progresses, with around 76% of those with dementia institutionalized before death. Providing good person-centred care in a range of different environments can be challenging.

Spiritual care helps people in their search for hope and meaning, particularly as they face issues of grief, loss and

uncertainty. However, because of cognitive changes, those with dementia may become dependant on others to maintain their spirituality (Ryan et al, 2005). Supporting the spiritual needs of families and carers is also important, as the suffering caused by dementia can last for many years with several losses experienced during that time. Although addressing such needs in those with severe dementia may be challenging, the spiritual needs do not stop with the onset of dementia.

End-of-life care

Several studies have looked at issues surrounding end-of-life care for those with dementia. Retrospective work carried out on a psychogeriatric ward showed that pain and breathlessness were the most common symptoms seen in the last 2 weeks of life. The palliation of these symptoms was variable with syringe drivers not being used even though patients were unable to take anything orally in the final 48–72 hours. The use of guidelines in a repeat audit demonstrated an increase in the number of patients prescribed analgesics and a decrease in the number of courses of antibiotics prescribed in the last week of life (Lloyd-Williams and Payne, 2002).

The NHS End of Life Care Strategy (Department of Health, 2008b) has been set up to improve the quality of care for people at the end of life. Three tools have been suggested by the strategy. The Preferred Priorities of Care Plan is a patient-held document outlining the patient's thoughts about his/her care, choices he/she would like to make and where he/she would want to die. The Gold Standards Framework in Care Homes Programme aims to identify, assess and plan care by promoting integrated collaborative working with primary care and specialist teams. The Liverpool Care Pathway for the dying aims to take the best of hospice care for the last days of life into different care settings. It addresses issues surrounding communication, symptom control and psychological support at the end of life. The use of the Liverpool Care Pathway in nursing homes can create a greater openness around death and dying and improve teamwork and communication (Hockley et al, 2005). High staff turnover in nursing homes and multiple GPs being involved in patients' care in the home may make implementation more challenging.

KEY POINTS

- Palliative care should be accessible to all with a life-limiting illness, including increasing numbers of patients with dementia.
- Those with advancing dementia may develop a wide range of problems including feeding difficulties, recurrent infections and symptoms that may be difficult to assess.
- Developing support for families, and attending to psychological and spiritual needs is also important for those with advanced dementia.
- A collaborative approach between all health-care professionals involved in the management of those with dementia is needed to enhance care.

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This article has described the wide variety of palliative care issues that may be faced by patients with dementia and the national initiatives to improve palliative care in dementia. It is worth emphasizing that palliative care is not something that can only be carried out by palliative care specialists but all those involved in the care of patients with advanced dementia. This might include psychiatrists, GPs, geriatricians and palliative care physicians as well as nurses, physiotherapists and speech therapists. Defining the terminal stage of dementia can be problematic, particularly as those with dementia do not necessarily deteriorate in an ordinal manner (Luchins et al, 1997). There may be palliative care issues occurring throughout the course of the illness, not just in the final few months. The identification of such issues also requires appropriate referral to those most able to deal suitably with them. There may not be a specific point during the illness where the emphasis changes from active to palliative care, rather there will be a balance of approaches depending on the specific situation (Murtagh et al, 2004).

The numbers of patients with dementia admitted to hospices are currently small with only 1–2% of admissions having dementia as the primary diagnosis (Davies and Higginson, 2004). The reasons for this are not clear; one possible reason may be the beliefs regarding which patients can be referred to hospices. It is possible, however, that many potentially suitable patients are not referred as there are concerns about removing them from their current environment and placing them in another which is not suited to those with dementia. If this is the case, then providing care to the level that might be achieved in a hospice environment should be attempted wherever that person is, whether it is his/her own home, a hospital or care home.

In order for this level of care to become a reality, adequate training and education is required which should include those who provide day-to-day care for those with dementia and also for the specialist teams that may also be involved. A collaborative approach between the different groups, sharing knowledge and expertise, has been suggested as a method of enhancing care. Therefore developing links between psychiatry of old age, palliative care and geriatric medicine is critical in providing coordinated palliative care for those with dementia. Although challenges remain, such as funding to develop already stretched services, the goal of improving palliative care for those with dementia remains an essential one. **BJHM**

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