Addressing the palliative care needs of people with dementia

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The palliative care needs of people with dementia have received little attention to date. In the early days of the disorder some drugs may assist with the cognitive and behavioural symptoms. However, as the disease progresses people with dementia become increasingly dependent on carers. Evidence suggests that a palliative care approach from diagnosis is beneficial because it addresses people’s emotional needs as well as those of their families and carers.

The longer we live the more likely we are to experience dementia and as life expectancy has increased so has the incidence of dementia. Dementia is a clinical syndrome, not a specific disease. It is evidenced through a set of symptoms, which classically include a decline in memory and thinking present for six months or more and of a degree sufficient to impair functioning in daily living (World Health Organization, 1993). There are many types of dementia resulting from a variety of disorders but Alzheimer’s disease is the most common form.

Alzheimer’s disease, in which nerve cells in the brain die due to abnormal structures called plaques and tangles, accounts for about 50 per cent of cases of dementia. Vascular dementia, accounting for 20 per cent of cases, is caused by small strokes (Sudbury, 2000). Alzheimer’s disease and vascular dementia can both exist in the same person (Burns et al, 2002). Other diseases or disorders that lead to forms of dementia include Huntington’s disease, Pick’s disease, and Down’s syndrome.

Prevalence

While estimates vary, a consensus of studies claims that there will be up to one million people with dementia in the UK by the end of the first decade of the 21st century. This may seem worrying at a time when the prospects of developing a pharmacological response remain remote (Morton, 1999). However, Burns (2000) claims that new pharmacological treatments for the underlying disease and its symptoms continue to be discovered.

The current service provision for people with dementia in England and Wales is estimated to cost between £9.5bn and £13.5bn annually in health and social care (Mchamee et al, 2001). These figures do not include the cost to carers in terms of time lost from work and from other activities (Jackson, 2002).

Effects of dementia

People with dementia share a range of disabilities characterised by the progressive loss of mental ability. The individual experiences difficulty communicating or completing everyday activities such as managing finances, shopping, or food preparation. As the dementia progresses basic functions such as mobility, continence, sleeping, and personal care may also be affected. Individuals may also experience visual hallucinations, depression, tremor, stiffness, and slowness of movement (Burgess and Page, 2003).

Occasionally these symptoms progress to the point where the person with dementia becomes physically aggressive or paranoid. She or he may lose the ability to recognise family members or complete the simplest of tasks, resulting in feelings of frustration and anxiety that can often lead to challenging behaviour (Box 1).

Communication is fundamental to human existence and being deprived of it can lead to social isolation, depression, despair, and disintegration of personality. Meaningful communication is a prerequisite for person-centred dementia care and its absence can lead not only to poor quality of life but also to a state of malignant social psychology as defined by Kitwood (1997). A state of social psychology is one that diminishes the essence of personhood. As a consequence, the person’s psychological needs are overlooked, communication becomes a low priority and care becomes a physical, task-oriented exercise. This has an enormous bearing on the way the person feels and behaves and has a correlation with challenging behaviour.

Effect on carers

In mild dementia the consequences of memory impairment may be minimal while in moderate or severe dementia it may be catastrophic, with the care usually falling mainly on family and friends. Caring for the person

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**Box 1. Behavioural Symptoms Associated with Dementia**

<table>
<thead>
<tr>
<th>Symptom</th>
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<tbody>
<tr>
<td>Aggression</td>
<td>Hallucinations</td>
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<tr>
<td>Agitation</td>
<td>Incontinence</td>
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<td>Apathy</td>
<td>Insomnia</td>
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<td>Attention-seeking</td>
<td>Resistance to care</td>
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<td>Delusions</td>
<td>Repetitiveness</td>
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<td>Disinhibitions</td>
<td>Restlessness</td>
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<td>Dysphasia</td>
<td>Screaming</td>
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with dementia can be very stressful and can take an emotional and physical toll on carers. Carer stress can also have an adverse effect on the behavioural symptoms of the person with dementia (Bryans, 2001).

As the illness progresses to the point where the affected person becomes physically and verbally abusive, the stress of caring can become too great resulting in the person with dementia being admitted to a long-term care facility for the remaining years of her or his life. Sudbury (2000) suggests that in the final stages of life only 20 per cent of people with dementia actually die at home. A life history booklet or diary, written by somebody who knows the person well and based on the person’s values and interests, may positively influence care when that person’s needs or wishes can no longer be verbally expressed.

**Dementia as a terminal illness**

Dementia can legitimately be seen as a terminal illness, as it is a degenerative disorder. Progression may be fast or slow but each person with dementia experiences the condition in an individual way and there is great variation in the progression of the illness (Smith, 2002).

The symptoms of a person with Alzheimer’s disease may progress slowly but steadily while those of a person with vascular dementia may progress more erratically. Coexisting illnesses may make decline more rapid. This means that the life expectancy of a person with dementia is difficult to predict. And although dementia is a life-shortening illness, another condition or illness may trigger death (Alzheimer’s Society, 2003). It is estimated that about 90 per cent of people with dementia ultimately die from pneumonia.

In the early stages of the illness, memory impairment, poor judgement, and apraxia may predispose the person to eating problems. Problems with controlling food or fluid orally and swallowing effectively (dysphasia) are common and can occur at any time as the disease progresses, putting the person at risk of choking. There may also be damage to the osmoreceptors, which control the body’s thirst mechanism. This prevents individuals from satisfying their thirst or letting others know that they are thirsty, resulting in dehydration (Brown, 2002).

Falls are not uncommon in people with dementia and occur due to sensory deficits, poor coordination, visual and spatial problems, polypharmacy, and the side-effects of medication. The consequences of falls are often severe and may result in fractures and chest infections, which can be fatal.

**New concepts in dementia care**

In recent years a new philosophy towards the treatment of people with dementia has emerged. Traditionally attitudes towards dementia were fatalistic and negative with assumptions that nothing could be done for the person (Burgess and Page, 2003). Memory impairment was generally put down to being part of the normal ageing process and was ignored.

Understanding the experience of dementia has led directly to principles of inclusion, empowerment, and participation, which have influenced issues such as how dementia is assessed, how the diagnosis is shared, and what happens after diagnosis. Mental health nurses have become active in all these areas, fighting the old degenerative model of dementia and promoting the concept of positivity (Burgess and Page, 2003).

**Theoretical models of dementia care**

**Medical model**

The dominant model of dementia care is the medical one, which seeks to respond to the organic disease of the brain that results in neurological deterioration and cognitive impairments (Cheston and Bender, 1999; Kitwood, 1997). Downs (2002) contends that the medical view sees dementia as a condition about which nothing can be done and that this attitude dominated the thinking of health care professionals until the early 1990s.

Briggs and Ashkan (1999) offer a more positive view of the medical model, saying that it offers the possibility of an early diagnosis, which may enable individuals with dementia and their families to plan for the future.

**Social model**

The social model of care includes understanding the experiences of living with dementia and emphasising relationship-building and individualised care. Some studies have shown that with careful interviewing and support from other services, it is possible to empower people with dementia to speak for themselves (Sabat, 2002). Downs (2002) suggests we have just begun to listen to individuals with dementia. This change in perception has been called the ‘new culture of dementia care’ (Kitwood, 1997). Dementia, which has formerly been defined as a disease, is now being viewed as a disability.

Gilliard (2002) says the social model opens up possibilities for considering the impact we can have on the lives of people with dementia. Viewing dementia as a disability allows us to view the person with dementia as an individual actively coping with her or his own impairment and entitled to an adequate quality of life and comfort (Downs, 2002). There is a growing body of evidence to show that people are adapting to living with dementia (Sabat, 2002).

**Diagnosis**

A diagnosis of dementia should result in a focus on a person’s strengths and skills that can be utilised rather than their deficits (Burgess and Page, 2003). There is still poor public and professional awareness of dementia, its progression, and how to obtain an appropriate diagnosis. GPs tend to identify older people with dementia only during times of crisis, which could be avoided with earlier diagnosis and intervention.

Jacques (2000) states that high-quality, person-centred services should be available from the onset of dementia and throughout the illness, regardless of where the people and their carers live. However, dementia can be difficult to diagnose in its early stages. In many cases the...
symptoms may be mistaken and dismissed as depression, absent-mindedness or preoccupation.

The development of memory clinics around the country has assisted with assessment, diagnosis, and treatment, so that people with dementia and their families can live their lives to the best of their abilities. Memory clinics have pioneered the services required to introduce and manage the new drugs for Alzheimer's disease that need to be prescribed in the very early stages of the illness.

While confusion may preclude dialogue, dementia is like any other illness where most of the time people are aware that their mental powers are deteriorating and the debate continues as to whether the affected person has a right to know about their diagnosis and what is happening to them. Ham (1999) suggests that if people are not aware of their condition at an early stage they cannot make choices about their future care. People diagnosed with dementia may need time to come to terms with the diagnosis. Such time may prove valuable in allowing individuals to make any financial, spiritual, and medical decisions while they are still able to do so. However, philosophical arguments question whether advance directives can be addressed before a person knows how the illness will affect her or him.

The Alzheimer's Society believes that it is inappropriate for a person with advanced dementia to be given artificial hydration and nutrition for the sole purpose of prolonging life. The society believes that treatment should be given to people with dementia to maximise their quality of life and comfort, in line with the British Medical Association's guidelines on withholding and withdrawing treatment. A family's future planning could include this if a diagnosis is made early, whereas a late diagnosis may rob the person with dementia of the right to make decisions about her or his future and treatment (Bryans, 2001).

The palliative approach

Until recently palliative care mainly focused on the needs of people with cancer and their families. However, it is being increasingly used in the care of people with other progressive terminal conditions, such as neurodegenerative diseases. It is regarded as beneficial in improving the quality of life for people with dementia and their families (Cox and Keady, 1999).

In the earlier period of the illness a palliative approach may include education, counselling, and support for people with dementia and their families. Admiral nurses and community psychiatric nurses have the skills to do this and are usually involved with the families. Psychological services may offer memory retraining and there is evidence to suggest that cognitive therapy is beneficial to people with Alzheimer's disease (Teri and Gallagher-Thompson, 1991). Specialist and liaison nurses have also begun to work in acute hospital settings in order to educate and advise on issues in dementia care, working with staff, patients, and carers (Burgess and Page, 2003). For example, Manchester Mental Health and Social Care Trust runs a supportive postdiagnostic, six-week support group for people with dementia and their carers. Support may continue to be offered by Admiral nurses through liaison with other members of the multidisciplinary team such as psychiatrists, social workers, district nurses, and GPs. Care packages and respite care may also be suggested to alleviate carer stress.

Palliative care

As the physical condition of the person with dementia deteriorates, palliative care may be an option and GPs, district nurses, and palliative care teams can be involved in providing this. If other health problems arise it is important to remember that aggressive treatment will not alter the underlying dementia.

Decisions about transfer to hospital must be carefully considered. In dementia, it is not uncommon for the person to experience delirium when unwell. In this state, cognition worsens significantly, sleep and behavioural changes are affected, and falls and injuries are not uncommon. Delirium must be carefully assessed and sedating medications may have to be used. The focus must be adequate support and symptom management.

One of the important medical management issues in the care of the person with dementia is pain management. This is made difficult by the person's inability to report symptoms (Box 2). There is no evidence, however, that people with communication deficits are less sensitive to pain, although there is evidence to suggest that patients with cognitive impairment are less likely to receive analgesia (Scherder and Bouma, 1997).

Indicators of pain are often non-specific, reflected in changes of sleep, mood, eating, mobility, behaviour, and vocalisation. Agitated behaviours may be difficult to interpret, and consequently medication may be overused or underused (Access Economics, 2003). Frequently dementia is blamed for challenging behaviour rather than the issues of sepsis, dehydration, constipation or pain. There are various 'discomfort scales' available, which assess pain by looking at non-verbal expression of symptoms, for example, noisy breathing, negative vocalisation, sad or frightened expressions, and tense body language (Hurley et al, 1992).

Palliative care also addresses the emotional needs of patients and families. This approach is believed to be more effective than aggressive therapies, such as intravenous antibiotic therapy, PEG or gastric nasal feeds, which only serve to prolong the life of a patient who is terminally ill, and can only add to the trauma of death. When the final stages are reached, comfort, dignity, and quality of life are the top priorities (Sudbury, 2000).

During the dying process, families should benefit from participating in the care and they should receive support during and after death. At the time of death, it is important for relatives to celebrate the person's life as well as taking time to grieve (Sudbury, 2000).

In South Manchester University Hospital Trust a person will be put on the 'Care of the Dying Pathway' in their final days of life.

REFERENCES


This care pathway was adapted by Tina Foley and Fran Mellor from the Last Days of Life Pathway developed by Ellershaw et al. (1997) at the Royal Liverpool Hospital and can be used for any person dying in the trust regardless of diagnosis. It was first implemented in January 2000 and over 600 patients, including patients with dementia, have been placed on it.

The pathway focuses on the specific needs of each patient and her or his family. It ensures that symptoms are assessed, managed, and monitored systematically in accordance with evidence-based guidelines. Palliative care is about shifting the focus from cure to comfort and the Care of the Dying Pathway at South Manchester aims to reduce distress in both patient and carer. It follows protocols and guidelines recommended to alleviate pain, nausea, respiratory tract secretions, and agitation. Dying patients tend to tolerate symptoms very poorly because of their weakness and debility. The intensity of symptoms will readily escalate to very severe distress if they are not controlled.

The pathway focuses on a multidisciplinary approach and ensures that the nursing, medical, and support teams work with the patient and family to a clear plan. The information needs of the patient and family are assessed regularly and the psychological and religious aspects of care are given as much attention as the physical. After death the palliative care team offers support to the main carer or referral to bereavement counselling.

The way forward
Palliative care for the dying person with dementia has been a relatively neglected topic in relation to policy, planning, practice development, and training (Cox and Keady, 1999). There are significant gaps in professional knowledge, skills, and expertise but there is an opportunity to cross-fertilise the fields of dementia care for the benefit of all concerned.

Palliative care needs to take on a multidisciplinary approach. Although nurse and medical training address the issues of holistic care, in reality acute medicine tends to focus more on the physical aspects of care, and mental health on psychological approaches and treatment. Nurses working on mental health wards are aware that they often lack the skills and knowledge to address the physical symptoms caused by other conditions in the later stages of dementia, and hospice staff and general nurses admit they often lack the knowledge and skills on how to care for the cognitively impaired person who is agitated or distressed.

Working in partnership (Box 2) general nursing, mental health, and social services can care holistically for people with dementia and their families. The sharing of information (from social workers, speech and language therapists, dietitians, and physiotherapists, for example) should be encouraged.

Conclusion
People with dementia and their carers are entitled to as normal a life as possible. High-quality, person-centred services should be available from the first signs and throughout the illness, regardless of where people with dementia and their carers live. Evaluating the suffering of patients with dementia who, in the more severe stages, cannot speak for themselves is inherently challenging. Palliative care offers a number of unique contributions to the advancement of care at the end of life. Perhaps the most valuable contribution is by the team providing a holistic model of care that addresses the physical, psychological, spiritual, and social needs of all patients to the end of life.

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