A holistic approach to caring for people with Alzheimer’s disease


Summary
This article adopts a holistic view of Alzheimer’s disease. Biomedical, psychological and social aspects of the condition are discussed, and aetiology, epidemiology, diagnosis and treatment explored. A range of approaches to working with people with Alzheimer’s disease, based on a psychological model of dementia, is described including reminiscence and cognitive stimulation therapy.

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Aims and intended learning outcomes
This article aims to challenge ideas and assumptions about Alzheimer’s disease and to provide an introduction to alternative approaches to working with people with the condition. After reading this article you should be able to:

- Outline the efficacy of the different treatments available for people with Alzheimer’s disease.
- Discuss various psychological approaches that are useful in working with people with Alzheimer’s disease.
- Identify ways in which nursing practice can be enhanced for people with Alzheimer’s disease.

Introduction
Alzheimer’s disease and other types of dementia are of increasing relevance and importance to nursing. The population is ageing and the age-related nature of Alzheimer’s disease means that the incidence of the condition is increasing (Alzheimer’s Society 2007). This article focuses on individuals with Alzheimer’s disease but much of the discussion is relevant to other types of dementia.

Alzheimer’s disease is not only a concern for those working in older people’s services but is also a concern for all areas of care and clinical practice. An understanding of the needs of people with Alzheimer’s disease will be useful whether treating an unrelated problem or when directly treating the symptoms of the disease. Although usually defined as an organic condition this article proposes that Alzheimer’s disease is best understood as a complex condition with biomedical, psychological and social aspects.

The first part of the article examines current knowledge and understanding of Alzheimer’s disease. Biomedical and psychosocial understandings of Alzheimer’s disease are compared and discussed. The experiences of people with Alzheimer’s disease are also affected by the social environment and culture in which they live. Issues such as ageism and the stigma associated with Alzheimer’s disease are also considered.
mental health conditions are influential. The symptoms, behaviours and experiences of a person with Alzheimer’s disease are not only the result of brain damage but are also caused by interplay between organic damage and the social and psychological environment. The article focuses on various approaches to treating, supporting and working with individuals with Alzheimer’s disease.

Understanding Alzheimer’s disease

Alzheimer’s disease is one type of dementia. The term dementia is used to describe a set of symptoms that have a variety of causes. Alzheimer’s disease is the most common type of dementia in the UK and the Western world, although in other parts of the world the proportions of different types of dementia can vary (Jacques and Jackson 2000). Other common types include vascular dementia and dementia with Lewy bodies. Much of this article, apart from the specific biological detail, has relevance for all types of dementia.

Alzheimer’s disease is a degenerative neurological condition that affects the brain and is characterised by progressive deterioration in the person’s cognitive function. It is split into early onset and late onset disease depending on the age at which an individual develops the condition. Early onset dementia may have a more rapid progression than late onset dementia (Ueki et al 2001), although some studies do not support this (Kay et al 2000). The rate of progression is usually related to the underlying cause of dementia and the severity of the cause when it first affects the individual. There is some evidence that early onset Alzheimer’s disease leads to more severe and widespread neurochemical abnormalities and can progress more rapidly (Ueki et al 2001). It is still not clear, however, whether distinct forms of Alzheimer’s disease exist for older and younger people. The discussion on aetiology is relevant for both types.

Epidemiology

The following key statistics and facts were published by the Alzheimer’s Society in 2007:

- The prevalence of both early onset and late onset dementia increases with age, doubling with every five-year increase across the entire age range from 30-95 years (Table 1).
- Alzheimer’s disease is considered to be the dominant subtype, particularly among older people, and in women for both early onset and late onset dementia.
- Alzheimer’s disease accounts for 62% of all dementia and is more prevalent in women (67%) than in men (55%).

As the population of the UK continues to age and

<table>
<thead>
<tr>
<th>Age range (years)</th>
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(Alzheimer’s Society 2007)

Aetiology

The aetiology of Alzheimer’s disease is usually defined in biomedical terms. Three main organic changes take place in the brain (Masters 2005):

- Formation of amyloid plaques.
- Formation of neurofibrillary tangles.
- Impairment of the cholinergic system and other neurotransmitter systems.

Neurofibrillary tangles and amyloid plaques can be found in the brains of people who do not display the symptoms of Alzheimer’s disease, but a correlation is found between the amount and density of these structures and corresponding symptoms of the disease. This is a simplified picture of the organic effects of Alzheimer’s disease on the brain. Other changes include: diffuse and symmetrical atrophy of the brain; increasing levels of amyloid beta and tau proteins in the cerebrospinal fluid and blood; degenerative changes in the sensory parts of the brain; abnormal structures in the hippocampus; and overall neural loss (Masters 2005). Alzheimer’s disease presents a complex organic aetiology.

Symptoms

The symptoms of Alzheimer’s disease are varied and often described as progressing in stages. While this description can be useful from a
Recommended steps in the diagnosis of dementia

A detailed history should be taken and information from the person with dementia and his or her carer should be considered.

The Mini Mental State Examination can assist diagnosis but a more comprehensive cognitive test, such as Addenbrooke’s Cognitive Examination, will improve the assessment.

It is good practice to screen for co-morbid conditions that can mimick the symptoms of dementia, such as urinary tract infection, depressive illness and vitamin B12 deficiency (Jacques and Jackson 2000).

Brain imaging techniques may be useful as they can identify reversible causes of dementia and can aid the differential diagnosis of dementia. Various techniques are used including: computed tomography, magnetic resonance imaging, single photon emission computed tomography and positron emission tomography.

Neuropsychological testing is recommended in the diagnosis of dementia, particularly where the signs of dementia are not obvious clinically. (Scottish Intercollegiate Guidelines Network 2006)
following discussions on alternative approaches to care do not exclude a biomedical understanding of dementia but emphasise the need for a broader understanding.

**An alternative definition of dementia**

Kitwood (1997), a social psychologist, challenged the accepted biomedical definition of dementia. He proposed a more holistic approach defining dementia as a dialectic interplay between neurological damage and psychosocial environment. The effect of the psychosocial environment can be negative or positive, either increasing the negative impact of the neurological damage or reducing its affect on the individual’s cognitive and social abilities. This led to his formulation of the experience of dementia as having five key components:

Dementia = $P + B + H + NI + SP$

- $P$ represents the person’s personality or resources for action, $B$ his or her biography, $H$ his or her physical health, $NI$ his or her neurological impairment and $SP$ the social psychology that surrounds the person from day to day.

The experience of dementia is described as being unique to the individual and depends on the interaction of these various components (Kitwood 1997). The central concept in Kitwood’s work is ‘personhood’. This is defined as ‘...a standing or a status that is bestowed upon one human being, by others, in the context of a relationship and social being. It implies recognition, respect and trust’ (Kitwood 1997).

An individual’s personhood is threatened by neurological damage and poor psychosocial environments. The concept of people with dementia as different is challenged in this theory. Kitwood states that the problems of dementia do not result from individuals with dementia, but from social interactions where all involved are responsible. Kitwood’s theory gained prominence during the 1990s leading to discussion of the emergence of a ‘new culture of dementia care’ based on a psychosocial model of dementia (Kitwood and Benson 1995).

**Social aspects**

Our understanding of Alzheimer’s disease is also affected by the society in which we live, which in turn affects the experiences of people with the disease. The majority of people with Alzheimer’s disease are older. The dominant view in the UK of older people is that they are a burden on society and are perceived to be the cause of a ‘crisis’ in terms of costs for pensions and care (Innes 2002). This promotes negative images of older people and supports and reflects a culture of ageism (Bytheway 2005). The significant contributions of older individuals are often ignored. Ageism and the stigma attached to people with mental health problems, including Alzheimer’s disease and dementia, occur at all levels in society. The NHS and other care providers are not exempt.

Ageism includes prejudice through labelling and negative stereotypes, and discrimination through denial of opportunities and resources (Bytheway 2005). People interact differently with an individual once he or she has been labelled as having dementia (Harding and Palfrey 1997, Innes 2002). Sabat (2002) describes how the label ‘dementia’ and resultant changes in people’s expectations lead to an assumption that people with Alzheimer’s disease somehow lose themselves or their sense of self through the disease process.

Sabat (2002) concludes that much of an individual’s self does remain as the disease progresses. The problem lies in the focus on deficits and dysfunction by others rather than an actual loss of self. Sabat’s (2002) discussions on self and selfhood reflect Kitwood’s (1997) sentiments on personhood. Lowered expectations, stigma, ageism, poor listening and communication, and other social and environmental factors can exacerbate the symptoms of Alzheimer’s disease and other types of dementia.

To counteract the impact of negative social and cultural influences, there has been a move to consider dementia as a disability and people with dementia as citizens. Conceptualising dementia as a disability moves the focus away from individual deficits to ideas, such as rights, social inclusion and citizenship. The citizen approach to dementia is based on reciprocity (Marshall and Tibbs 2006). It asks: ‘What can people with dementia give to us?’ rather than ‘What can we do for people with dementia?’

**Time out 2**

Is ageism evident in day-to-day practice at your workplace? List some of the words and phrases used when talking about older adults and people with Alzheimer’s disease. Reflect on whether or not these words support positive images of older people.

**Care, support and treatment**

The following sections focus on different approaches to treating and caring for people with Alzheimer’s disease. The sections reflect the different ways of understanding dementia discussed above, starting with medical treatments and moving on to psychological and social approaches to care.
Use of medication There are four drugs used in the treatment of Alzheimer’s disease and other types of dementia: donepezil, galantamine, memantine and rivastigmine.

Donepezil, galantamine and rivastigmine are acetylcholinesterase inhibitors. Acetylcholinesterase is an enzyme that controls the level of neurotransmitters in the brain. In Alzheimer’s disease inhibiting this enzyme promotes the amount of neurotransmitters in the brain and can improve brain function. Memantine acts in a different way, helping to restore glutamate signal transmission.

There have been many clinical trials and other studies examining the efficacy of these drug treatments with mixed results. Olsen et al (2005) reviewed 27 studies and concluded that in relation to Alzheimer’s disease:

- Donepezil, galantamine and rivastigmine are better than a placebo in patients with mild to moderate Alzheimer’s disease and the global clinical improvement is improved for one year or longer.
- Memantine is better than a placebo for people with severe dementia.
- Galantamine can improve behavioural symptoms.

Hansen et al (2007) reviewed 14 studies involving people with Alzheimer’s disease and found that all of the drugs used were better than placebo and that their effects were not changed significantly by age, disease severity, gender or drug dose. Overall the effects of the drugs are found to be modest. Hansen et al (2007) discussed the problems with the outcome measures currently used to measure effectiveness. An individual may show significant improvement on one or two items of a scale but this improvement might not be evident in his or her overall score. Therefore, it is difficult to obtain an accurate picture of the efficacy of these drugs.

Lecanu and Papadopoulos (2007) state that future treatments need to be multi-therapeutic because of the complex aetiology of Alzheimer’s disease. A major problem is that diagnosis cannot be made early enough to use many innovative treatments.

Some would suggest that the focus on specialist drugs has taken valuable resources away from other services and possible therapeutic approaches to Alzheimer’s disease, and has only produced minimal beneficial effects for most individuals who take the drugs (Pelosi et al 2006). This is often justified by the argument that these drugs are the only treatment available for people with dementia (Pelosi et al 2006). This article, along with a vast range of other research literature, illustrates a variety of positive approaches to working with people with dementia which enhance quality of life and reduce symptoms.

The dominance of the biomedical model that was challenged by Kitwood and Benson (1995) may be taking precedence again as a result of the promotion of these drug treatments. However, this is not necessarily a positive step for people with Alzheimer’s disease and other types of dementia. A narrow focus on the biological aspects of Alzheimer’s disease limits understanding and may have negative consequences for people with the condition.

Many other drug treatments are used with the aim of reducing or alleviating the symptoms of Alzheimer’s disease but these have mixed results and possible adverse side effects. Concerns about the use of other drugs such as antidepressants, tranquillisers and psychoactive drugs for people with dementia include: over-prescription, dependence, adverse side effects, possible misuse, their association with increased cognitive decline, increased risk of falls and the restricted nature of their efficacy (Moniz-Cook et al 2003).

Therapeutic approaches Researchers and practitioners in psychology and social sciences have been involved in expanding our understanding of Alzheimer’s disease and providing interventions and approaches for working with people with the disease for many years. Approaches have been popularised, critiqued and gone in and out of fashion. The next section focuses on three therapeutic approaches – person-centred care, cognitive stimulation therapy and reminiscence – which have achieved lasting salience when working with people with Alzheimer’s disease.

Person-centred care Person-centred care, person-centred nursing and person-centred planning are all terms that are commonly used in care for people with all types of dementia. All of these draw on Kitwood’s (1997) conceptualisation of dementia and theory of personhood. There is, however, a lack of consensus on what the terms mean in practice.

Brooker (2004) highlights that, although the term person-centred care is used widely by policy makers and practitioners in dementia care, there is a lack of consistency in how it is understood. McCormack’s (2004) review of person-centred gerontological nursing concludes that there has been little research on what person-centred...
nursing means despite widespread use of the term. Brooker (2004) proposes four elements that should be included to produce person-centred care:

- Valuing people with dementia and those who care for them.
- Treating people as individuals.
- Looking at the world from the perspective of the person with dementia.
- A positive social environment to enable the person with dementia to experience relative wellbeing.

McCormack (2004) concludes that person-centred nursing has four aspects:

- Being in relation (social relationships).
- Being in a social world (biography and relationships).
- Being in place (environmental conditions).
- Being with self (individual values).

Person-centred care encourages people interacting with individuals with Alzheimer’s disease to remember that they are first and foremost people, not a manifestation of a disease. The approach guards against ‘malignant social psychology’, as defined by Kitwood (1997), and encourages a proactive approach in communication and understanding for people with dementia.

**Cognitive stimulation**

Cognitive stimulation therapy (CST) has developed from other approaches such as reality orientation. There is growing evidence for the efficacy of CST in reducing cognitive impairment and, in some cases, improving quality of life (Orrell et al 2005, Woods et al 2006). CST usually involves group work concentrating on guided conversations and other activities such as word games. CST sessions also often include an element of reality orientation to time, place and person. A common drawback to this type of approach is that the therapeutic sessions are not continued, perhaps because of cost or availability. Orrell et al (2005) found that the best outcomes for people with dementia are obtained when weekly maintenance sessions are offered. Research also suggests that sessions offered in a social context and offering global or multisensory stimulation have the best outcomes (Moniz-Cook 2006).

There are increasing numbers of cognitive therapies available for people with dementia. These include memory training, memory rehabilitation and memory stimulation (Moniz-Cook 2006). Elements of these approaches could be incorporated into daily nursing practice to improve interaction with, and care for, people with Alzheimer’s disease.

**Reminiscence**

Since the 1960s it has been understood that reflection on, and discussion of, past experiences are important parts of the lives of older people, particularly those with dementia. Reminiscence in different forms can help older people reconnect with who they are and help them cope with and understand current experiences. Reminiscence can be undertaken in many different ways. More structured approaches include life review, life story work and group work. Some form of life story is now a common part of care plans in residential and other care settings. Reminiscence can provide comfort and enjoyment (Royan 2003) or can be used more skilfully in a psychotherapeutic approach (Gibson 1994).

**Time out 4**

Speak to an occupational therapist or psychologist about their work with people with Alzheimer’s disease or other types of dementia. Do they use person-centred care, cognitive stimulation, reminiscence and/or any other approaches? How does their understanding of Alzheimer’s disease compare with yours?

The clinical evidence for the efficacy of life story work and reminiscence is limited but this is often the result of methodological inconsistencies making it difficult to find consensus between different studies (Moos and Bjorn 2006). Different studies focus on different outcomes such as wellbeing, enjoyment and increased interactivity.

Finnema et al (2000) found that reminiscence had generally positive outcomes, particularly when the focus was on the emotional content of memories. There is also evidence that staff can benefit from reminiscence and their work and relationships with older people improve through better understanding (Woods and McKiernan 1995). In an environment where there may be little social stimulation, such as an acute hospital ward, simple use of reminiscence can have a strong positive impact, helping staff to connect with and understand the people they are working with and thereby improve the care provided (Woods and McKiernan 1995). Elements of these approaches can be incorporated into daily practice.

**Time out 5**

Write a list of symptoms you associate with Alzheimer’s disease. What do you think are the reasons for these different symptoms? Have your ideas changed since the first Time out activity?
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Conclusion
This article introduces different approaches to understanding Alzheimer’s disease. Readers can increase their knowledge by reading additional information by the key authors referenced here. Alzheimer’s disease is a complex condition and an individual’s symptoms and experiences are not only affected by organic brain damage but also by his or her psychosocial environment and culture. Alzheimer’s disease can be described as having a complex aetiology with both organic and psychosocial aspects leading to different ways of understanding and conceptualising the condition. It is important to remember that social and cultural norms and attitudes can have a strong, negative effect on the experiences of people with Alzheimer’s disease.

There are many approaches to treatment and support reflecting the different conceptualisations of the condition, including those discussed in this article. It is only by understanding the different influences on the experiences of people with Alzheimer’s disease that nurses can provide sensitive and appropriate support and treatment whatever the setting and whatever the needs of the individual NS.

References
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