Changing attitudes in dementia care and the role of nurses

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Dementia care has been seen as a low priority, but with an estimated 700,000 people in the UK with dementia and an ageing population this is changing. The Alzheimer’s Society will be holding events this week to raise awareness of dementia, sending a strong message to policy makers that dementia is a serious health issue. Nurses have also become active in fighting the old degenerative model of dementia and promoting the concept of person-centred care.

In the past dementia was perceived as an illness with low priority and was greatly misunderstood by society. Traditionally, attitudes towards dementia were fatalistic and negative with assumptions that nothing could be done for the person.

In the early stages of the illness memory problems were generally put down to being part of the normal ageing process and were often ignored. This has changed, mainly due to the work of the late Tom Kitwood, who was professor of psychogerontology at Bradford University, and worked towards achieving a person-centred approach to dementia care. Dementia is now viewed as the cutting edge of mental health services, where changing cultures of care with a focus on people’s strengths and individuality, rather than their deficits, is actively encouraged. The social model of care now complements the medical model of care, in recognition of the fact that knowing patients’ life histories and personality can assist in understanding people with dementia and so improve their well-being.

Defining dementia

Dementia is a clinical syndrome 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). From the onset the individual experiences difficulty with communication or in the completion of everyday activities such as managing finances, shopping or food preparation. As the disease progresses, basic functions such as mobility, continence, sleeping and personal care may also be affected. Individuals may experience mental health problems such as visual hallucinations or depression and also, in some cases, develop physical problems such as a tremor, stiffness and slowness of movement.

Prevalence of dementia

It is conservatively estimated that 700,000 people in the UK have dementia. The incidence of dementia increases with age and is thought to double every five to six years after the age of 65, but there are about 18,500 people under 65 with dementia in the UK.

Service provision to people with dementia in England and Wales costs over £1bn annually in health and social care. In a general hospital it is thought that 30 per cent of older people have cognitive impairment, while one in 30 of those admitted will be affected by established or incipient dementia.

Dementia is therefore common in the older adult population and cognitive impairment is particularly common within the acute care setting. This is not likely to change in the near future as demographic studies predict a steady increase in the average age of the population over the course of this century and a rise in the number of people with dementia that reaches almost one million in the UK by 2020 (Alzheimer’s Disease International, 1999).

Raising awareness

World Alzheimer’s Day was launched, with the support of the World Health Organization (WHO), on 21 September 1994 at the opening of Alzheimer’s Disease International’s 10th annual conference in Edinburgh.

Alzheimer’s Disease International envisaged that an annual awareness day would unite opinion leaders, people with dementia, their carers and families, medical professionals, researchers and the media from all around the world. The organisers thought that by having a globally coordinated awareness day they could send a strong message to governments and policy makers alerting them to the fact that dementia is a serious health issue, which will have major implications on services and health systems around the world.

Evaluating the impact of health promotion events is notoriously difficult (Ewles and Simnett, 1999). However, last year’s World Alzheimer’s Day was regarded as being successful because:

- Some 47 countries organised an event;
- The average number of daily visitors to the organisation’s website (www.alz.co.uk) almost doubled on the day (from 372 to 667);
Evaluations collected from members and others who organised events showed an increase in the impact (media coverage and enquiries) from previous years; there was a significant increase in the number of individuals joining around 21 September as a result of the increased awareness.

This year’s campaign
To mark World Alzheimer’s Day this year the Alzheimer’s Society is holding its first national Memory Walk event, where groups from the society will organise walks on or around 21 September. The Memory Walk is a fundraising and awareness-raising event to support people affected by dementia. The idea was first launched in the USA in 1989, and has been adopted by a number of other countries worldwide.

New treatment philosophy
In recent years there has been an emergence of a new philosophy towards the treatment of people with dementia. While the roots of this person-centred culture lie within social psychology it is nursing that has sought to apply philosophical principles into real and innovative professional practice and in doing so has developed an evidence base drawn from many excellent qualitative research studies.

Understanding the lived experience of dementia has led directly to principles of inclusion, empowerment and participation, which have steadily influenced issues such as how dementia is assessed, how the diagnosis is shared, and what happens after diagnosis. Nurses have become active in all these areas fighting the old degenerative model of dementia and promoting the concept of positivity. Dementia is no longer an illness that people die from but a disability that people can learn to live with. It is no longer a collection of deficits but of retained strengths and abilities that can be utilised.

A raised profile for nurses
Nurses have started to take a more dynamic stance in supporting people with dementia and their families to live their lives as best as they are able. Memory clinic nurses have pioneered the services required to introduce and manage the new drugs for Alzheimer’s disease, often to those in the very early stages of illness. Admiral nurses (specialist dementia nurses working in the community) and community psychiatric nurses offer highly effective education, counselling and support.

Dementia specialists and liaison nurses have begun working in acute hospital areas advising on the delivery of quality care. Dementia care nurses in many wards and nursing homes actively pursue improved quality of life for patients and residents through individualised care, emphasising purposeful activity and meaningful communication. Nurse researchers in academic centres are constantly evaluating the impact of innovative practice, while growing numbers of consultant nurses are pushing the boundaries of professional nursing practice into new and challenging areas.

Dementia care has therefore distanced itself from a very old culture that regarded it as a backdrop with high physical demands but few challenges, well suited to those of limited ability and questionable competence. In doing so dementia care has become a dynamic specialty held together by the strength of the relationship that develops between nurse, person with dementia and his or her family. Dementia should not be ignored, the person with dementia should be heard and the government is currently addressing this in its proposal for new mental health incapacity legislation.

The draft mental incapacity bill
People with dementia and their carers have campaigned for over a decade for new legislation regarding mental capacity. The largest group of adults affected by incapacity are those with dementia. Decisions regarding the capacity of patients with dementia are often complicated by other conditions such as depression.

The draft mental incapacity bill (Secretary of State for Constitutional Affairs, 2003) puts into law the principle that all adults are assumed to have the capacity to make decisions for themselves.

On Tuesday 16 September 2003 the Alzheimer’s Society, as part of the Making Decisions Alliance, gave oral evidence to the Joint Committee on the draft mental incapacity bill. The Alzheimer’s Society had already submitted written evidence on the bill and their response is based on the comments and experiences of the society’s branches and members and this is available on their website (www.alz.co.uk).

The Alzheimer’s Society welcomes the draft bill, which promises to give people with dementia more control over issues such as:
● The treatment they receive;
● How they spend their money;
● Where and how they live;
● Planning for the future and who they would like to make day-to-day decisions on their behalf when they are no longer able to do so.

However, the society has said that it would like to see the bill renamed as the Mental Capacity Bill to reflect the presumption of capacity that is sustained in the bill. The society also highlights the fact that people with dementia and their carers may not be able to benefit from new legislation unless early diagnosis improves.

Future prospects
Dementia is a common condition, which due to the ageing profile of the population will become more common. The Alzheimer’s Society is raising awareness, supporting research and influencing policy. The greatest challenge for nurses remains the implementation of the new culture of person-centred care for patients with dementia against a backdrop of organisational change, financial constraints and competing health care priorities.

For more details about World Alzheimer’s Day see Alzheimer’s Disease International’s website: www.alz.org/adi/wad

REFERENCES