Challenging the stigma of Alzheimer's disease

Susan M Benbow, Darren Reynolds

Changing Minds — Every Family in the Land ***is a national campaign launched by the Royal College of Psychiatrists which aims to reduce discrimination against people who suffer from mental disorders. One of its target areas is dementia. What is the stigma associated with Alzheimer's disease and how can hospital doctors challenge it in everyday practice?***

Stigmatization is the process of labelling someone: it marks someone out as different, as less of a person (Byrne, 1999). People who have mental illnesses are regarded as different because of their illness, the treatment they receive and their contact with psychiatric services. They may be blamed for bringing on their own illness or seen as being 'victims of bad fate, religious and moral transgression, or witchcraft' (Microsoft Encarta, 1998). People who are old are stigmatized because of their age. Being old and having mental illness may involve double stigma or 'double jeopardy'. Herrick et al (1997) regard stigma as contagious, in that those who have contact with the stigmatized person are also stereotyped. Thus psychiatric and geriatric medical nurses may be regarded as having lower status than medical and surgical nursing colleagues.

A related concept is that of prejudice. Cecchin et al (1994) define prejudice as a preconceived preference or idea, a bias. They argue that people cannot avoid having prejudices, although they can be aware of them, be prepared to change them and be aware that others may have different, equally valid biases of their own. This is true across the whole of medicine (and perhaps the whole of life). It may be useful to think of stigma in terms of people's prejudices.

PREJUDICES ABOUT ALZHEIMER'S DISEASE

Alzheimer's disease (AD) was initially a term applied to a form of early onset dementia, but over recent years the term has become associated with dementia in late life (Kitwood, 1997). Kitwood (1997) has suggested that the extended use of the term may have alleviated some of the stigma associated with cognitive decline in later life, in that it implies a medical, potentially treatable condition.

This may be true but, although AD involves changes in brain structure and chemistry, unlike other neurological conditions, it is placed within the field of psychiatry and attracts the stigma of a psychiatric illness. Kitwood (1997) argued that people with dementia are depersonalized because they are seen as old ('incompetent, ugly and burdensome'), as dependent and frail, and as mentally unstable to the point where they enter the realm of 'loss of self'. Contact with them activates anxieties among others which lead to avoidance and exclusion, perhaps as a defensive reaction. O'Rourke (1996) regarded AD as a metaphor for contemporary fears of ageing, but pointed out that even the majority of old people do not have a dementia. If being old and mentally ill involves double jeopardy, the additional cognitive impairment of AD may generate triple jeopardy.

HOW DO PREJUDICES AFFECT DIAGNOSIS?

Prejudices about cognitive impairment in late life may affect how far health professionals investigate a person to obtain an accurate diagnosis. Marzanski and Jolley (1999) state that general practitioners are faced with three challenges: to encourage people with memory problems to come forward for investigation, to undertake appropriate investigation and establish a diagnosis, and to provide appropriate treatment and support when a dementia is confirmed.

Memory problems may, however, emerge only after a person has been admitted to a medical or surgical ward for a concurrent condition. The

Dr Susan M Benbow is Consultant Psychiatrist (Old Age Psychiatry) and **Dr Darren Reynolds** is Specialist Registrar in Old Age Psychiatry, Central Manchester Healthcare NHS Trust, Carisbrooke Resource Centre, Gorton, Manchester M12 5LF

Correspondence to: Dr SM Benbow

stigma of old age is such that memory problems may be assigned to dementia without investigation, as if dementia is a natural component of the ageing process.

A similar problem occurs when health-care workers assume that someone with dementia is too old or too forgetful to benefit from treatment for a physical illness, and/or that they are too confused to express a view about physical treatment or aspects of their future life (such as where they will live after discharge from hospital).

In reality, investigation allows treatable physical illnesses, such as vitamin deficiencies, endocrine disorders and chronic infections, and treatable mental illness, such as depressive illness, to be identified. Other contributory factors can be considered, including drug and alcohol use. Even when the person has an established diagnosis of dementia, investigations may sometimes be indicated as their cognitive function may be worsened further by active illness, prescribed or illicit drugs or alcohol misuse. A person whose memory is impaired will appear to be more confused than is their norm in hospital, since they will have lost their usual routine and environmental and social cues. In order that changes in function can be identified, rather than inevitable deterioration being assumed, assessment must involve obtaining information about the person's function before, and during, their hospital admission.

DISCLOSING THE DIAGNOSIS

A medical/biological diagnosis may help to decrease stigma (Lawrie, 1999), but many relatives of people with AD do not want them to be told their diagnosis, despite the fact that, paradoxically, they would wish to know if they themselves had developed the disease (Maguire et al, 1996). In a study of community elders (Holroyd et al, 1996) a majority stated that they would wish to know if they had AD.

Kirby and Maguire (1998) regarded the resistance of family members as the greatest barrier to disclosing the diagnosis of AD to the person involved. Reasons suggested for this include generational differences (coming generations will more often expect to be told their diagnosis), parental protection of the person with a dementia (which may itself relate to our prejudices about AD), and a fear that relatives may be unable to deal with the person's reaction and grief at the diagnosis (Maguire et al, 1996). One concern of relatives may be possible suicidal ideation or the wish to die (Draper et al, 1998).

One widespread belief about dementia is that nothing can be done about it. This belief is under increasing challenge. Donepezil was the first acetylcholinesterase inhibitor licensed for use in AD in the UK from April 1997 (Kelly et al, 1997). Its introduction opened up the possibility of offering a drug treatment for those with mild to moderate AD and has probably increased the already growing practice of talking with people about their diagnosis of AD in order that they are able to make decisions about drug treatment and other aspects of their management (including legal matters such as enduring power of attorney and advance treatment directives).

The availability of drug treatments offers hope to patients, families and health-care teams (Filley et al, 1996), and an active role in the fight against AD. The evidence is that people with terminal illnesses, including AD, want to be told their diagnosis, but that doctors and relatives are reluctant to tell them (Clafferty, 1999). Thus they may deprive people of the possibility of potentially effective drug treatment, of choosing social and psychological supports, of putting their affairs in order and making arrangements for their future care.

COPING WITH DEMENTIA

As doctors increasingly talk with people about their diagnosis of AD, there is increasing information about the experience of the person with dementia and their views on treatment offered to them (Williams, 1999). The need for consent to drug treatment should mean that people with AD will be offered more information about the condition and more discussion about management and prognosis. If health-care professionals attempt to be sensitive to their own prejudices and those of others they will be open to other ways of understanding the 'problems' of AD, which do not see them as part of an inevitable decline.

Phinney (1998) identified two main themes in an investigation of the patient's perspective. One was the experience of 'being unsure' which involved memory loss, conversational difficulties, disorientation and fluctuating awareness. The second was the struggle involved in 'trying to be normal' despite their illness by keeping an active mind, self-monitoring, maintaining engagement in social and other activities and downplaying difficulties. Awareness of these themes can help health-care workers to understand some of the behaviours of people with AD and can allow negotiation of support systems and means to help people cope.

Bahro et al (1995) identified a number of different coping strategies among people with AD including mourning, denial, minimizing, blaming oneself and externalizing memory functions (e.g. by using notes or lists). Phinney (1998) argues that people with dementia can speak for themselves when given the opportunity and that this has far-reaching implications.

Health-care professionals need to tailor their practices to the level of understanding that individuals have of their AD and their day-to-day coping strategies, and not assume that people with a diagnosis of AD lack the capacity to make any decisions. Even in advanced AD a person may have capacity to make some decisions for themselves if given the opportunity (Law Commission, 1993). Doing this allows people coping with dementia to be fully involved in their own care.

MANAGEMENT ON MEDICAL AND SURGICAL WARDS

Health-care professionals' prejudices about late life and dementia may affect how people with AD are managed on medical and surgical wards. *Table 1* sets out principles of ethical care of people with AD or other dementia (Post, 1995). From these can be drawn out a series of action points for health-care professionals caring for people with dementia on medical and surgical wards.

Diagnosing and treating medical/surgical conditions

Physical illnesses will tend to worsen the function of an individual with AD. It is important to diagnose and actively treat any illnesses as they may be worsening the cognitive function of an individual with AD. In making decisions about whether or not to offer treatment for independent medical or surgical conditions, it is necessary to avoid prejudiced assumptions, e.g. that a person could not benefit from a hip replacement because they are forgetful, or that someone should not be resuscitated because they have a diagnosis of early AD. Treatment may make a difference between the person continuing to live independently in their own home and having to move prematurely into residential or nursing care. Low expectations of recovery and rehabilitation are self-fulfilling and are one of the prejudices identified in health care of elderly people (Health Advisory Service 2000, 1998).

Establishing an accurate diagnosis of a dementia

Some people will have been investigated and the diagnosis of their cognitive impairment will be clear. Others may present anew and full assessment and investigation will be needed to establish whether or not they have a dementia syndrome and, if they do, what the likely diagnosis is.

Establishing a functional baseline

On a hospital ward people will tend to function below their baseline because of the different environment and change in their routine. Assessment involves obtaining information about their function before the medical or surgical illness which led to hospital admission. It is important not to assume that people who are confused in hospital were confused and unable to function in their home environment. People always look worse in hospital. Assessment will involve liaison with carers, family and any health and social care professionals who are or have been involved with the person concerned.

Involving the individual and respecting their wishes

The functional approach to decision making involves asking whether a person is able at a particular time to understand the nature and effects of the decision (Law Commission,

TABLE 1.
Principles of ethical care of people with Alzheimer's disease

Something can be done for people with AD
Many factors cause excess disability among individuals with AD. Identifying and changing these factors will reduce excess disability and improve the person's function and quality of life
People with AD have residual strengths. Building on these strengths will improve the individual's function and quality of life
People with AD express understandable feelings and needs through their behaviour and responding to those feelings and needs will reduce behaviour problems
Aspects of social and physical environment affect function of people with AD. Appropriate environments will improve an individual's function and quality of life
Addressing the needs of individuals with AD and the needs of their families, and involving families in the care of individuals with AD, will benefit all concerned

AD = Alzheimer's disease. From Post (1995)

1995). This approach allows for fluctuating or partial capacity to make decisions and allows people with cognitive impairment to be involved in making decisions about their care as far as they can. It means that health-care staff have a responsibility to involve people in their own care and recognize and respect their wishes as far as possible.

Involving the family and respecting their wishes

AD has effects throughout the family and involving the family is accepted good practice. One of the National Charter standards is that health authorities should ensure that relatives and friends are informed about the progress of a person's treatment, subject to their wishes. Difficulties arise when the family and individual concerned have conflicting views. It helps to be open with families, to be clear about each person's views and the decisions for which they are responsible.

Changing attitudes

White (1998), in an editorial about the stigma of mental illness, stated that in medicine we need to get our own house in order. Negative attitudes towards people with AD and other dementias are widespread in all areas of medical practice. Negative attitudes lead to failures to establish diagnoses, to treat medical and surgical conditions, to involve people in decisions about their care and to offer treatment and support, which can result in premature nursing and residential home placements. This is an exciting time in working with people with AD. Donepezil is likely to be the first of a number of drug treatments and psychological treatments are being increasingly offered to individuals and families (Benbow et al, 1993; Long, 1997).

CONCLUSIONS

Health-care professionals must address their own misconceptions and those of others if they are to offer holistic and thoughtful care to people with AD and their families. To paraphrase the Health Advisory Service 2000 report (1998), patients, their relatives and staff must all take responsibility for assertively challenging negative views about dementia, old age and the propensity for ill health, particularly the belief that prospects for helping are gloomy. **HM**

Conflict of interest: none.

Bahro M, Silber E, Sunderland T (1995) How do patients with Alzheimer's Disease cope with their illness? — a clinical experience report. *J Am Geriatr Soc* **43:** 41–6

Benbow SM, Marriott A, Morley M, Walsh S (1993) Family therapy and dementia: review and clinical experience. *Int J Geriatr Psychiatry* **8:** 717–25

Byrne P (1999) Stigma of mental illness Changing minds, changing behaviour. *Br J Psychiatry* **174:** 1–2

Cecchin G, Lane G, Ray WA (1994) *The Cybernetics of Prejudices in the Practice of Psychotherapy.* Karnac Books, London

Clafferty RA (1999) Dignity in knowledge. Informing patients with Alzheimer's Disease about their diagnosis. *Psychiatr Bull* **23:** 394–6

Draper B, MacCuspie-Moore C, Brodaty H (1998) Suicidal ideation and the 'wish to die' in dementia patients: the role of depression. *Age Ageing* **27:** 503–7

Filley CM, Chapman MM, Dubovsky SL (1996) Ethical concerns in the use of palliative drug treatment for Alzheimer's disease. *J Neuropsychiatry Clin Neurosci* **8:** 202–5

Health Advisory Service 2000 (1998) *Not because they are old.* An independent inquiry into the care of older people on acute wards in general hospitals. Department of Health, London

Herrick CA, Pearcey LG, Ross C (1997) Stigma and ageism: compounding influences in making an accurate mental health assessment. *Nursing Forum* **32:** 21–6

Holroyd S, Snustad DG, Chalifoux ZL (1996) Attitudes of older adults on being told the diagnosis of Alzheimer's disease. *J Am Geriatr Soc* **44:** 400–3

Kelly C, Harvey R, Cayton H (1997) Drug treatments for Alzheimer's disease. *Br Med J* **314:** 693–4

Kirby M, Maguire C (1998) Telling the truth. *Br J Gen Pract* **48:** 1343–4

Kitwood T (1997) *Dementia Reconsidered. The Person Comes First.* Open University Press, Buckingham

Law Commission (1993) *Mentally Incapacitated Adults and Decision-making.* Medical Treatment and Research Consultation Paper No 129. HMSO, London

Law Commission (1995) *Mental Incapacity.* Report Number 231. HMSO, London

Lawrie SM (1999) Stigmatisation of psychiatric disorder. *Psychiatr Bull* **23:** 129–31

Long J (1997) Alzheimer's Disease and the family: working with new realities. In: Hargrave TD, Hanna SM, eds. *The Aging Family New Visions in Theory, Practice, and Reality*. Brunner/Mazel, New York: 209–34

Maguire CP, Kirby M, Coen R et al (1996) Family members' attitudes toward telling the patient with Alzheimer's disease their diagnosis. *Br Med J* **313:** 529–30

Marzanski M, Jolley D (1999) Changing minds addressing the stigma of Alzheimer's disease. *Geriatr Med* **29:** 27–31

O'Rourke N (1996) Alzheimer's Disease as a metaphor for contemporary fears of aging. *J Am Geriatr Soc* **44:** 220–1

Phinney A (1998) Living with dementia from the patient's perspective. *J Gerontological Nurs* **June:** 8–15

Post SG (1995) *The Moral Challenge of Alzheimer Disease.* The Johns Hopkins University Press, Baltimore and London

White PD (1998) 'Changing Minds': banishing the stigma of mental illness. *J R Soc Med* **91:** 509–10

Williams D (1999) John's story. *Alzheimer's Disease Society Newsletter* **June:** 5

KEY POINTS

- Establish a diagnosis.
- Diagnose and treat medical/surgical conditions.
- Establish a functional baseline.
- Involve the individual and respect their wishes.
- Involve the family and respect their wishes.
- Challenge negative views.