

A quiet revolution



LINDA CLARE, ALAN BADDELEY, ESME MONIZ-COOK and BOB WOODS discuss advances in the understanding of dementia.

DEMENTIA is '*prima facie* a psychological disorder' (Morris & McKiernan, 1994), but the psychological needs of people with dementia are often ignored. Why is dementia a neglected area for psychologists? Perhaps, for many, the word *dementia* conjures up a sense that nothing can be done. It is true that at present there is no means of curing dementia or preventing its ultimate progression; however, the first pharmacological treatments are now available, and this article will illustrate that there is a great deal that can also be achieved from a psychological perspective.

Indeed, in recent years a quiet revolution has taken place in dementia care. Psychologists working in this field have been instrumental in developing both theory and practice, and in expanding the research evidence base. Here we explore some of the ways in which psychologists are helping to understand and meet the challenge of dementia.

The dementia 'signature'

Most forms of dementia eventually progress to the stage where they impact on many and perhaps all cognitive functions (see box), but during the early stages different types of dementia have different 'signatures' in terms of the pattern of impairments. These signatures can in turn be distinguished from those of other conditions that may affect cognitive

function, such as depression. Neuropsychological and neuroimaging research aimed at understanding these patterns means it is possible to detect dementia at an increasingly early stage. This creates opportunities for early intervention, and may in time help in the development of preventive strategies, as

'Dementia is more than simply a matter of brain decay'

well as offering opportunities to address theoretical questions about brain mechanisms and cognitive processes.

To illustrate the concept of specific signatures, let's take the early stages of Alzheimer's disease. Here, understanding memory is key to making sense of the cognitive changes involved. Memory is not a simple, unitary faculty. One important component is the central executive or attentional control system, and this is particularly affected in the case of Alzheimer's (Morris, 1996). Experiments have shown that people with Alzheimer's have a particular problem in combining two tasks, even two simple tasks (Baddeley *et al.*, 1991). In everyday terms, they will have difficulty in keeping track of a conversation if there are several people taking part, or if they are required to do

two things, like walking and talking at the same time. This is potentially useful in early detection of Alzheimer's, and it is also helpful in advising carers and people with dementia.

However, by far the greatest impairment in Alzheimer's is in episodic memory (Brandt & Rich, 1995). Episodic memory allows people to remember events that have happened in their life and link these with the context in which they were experienced. It is a powerful system but rather fragile; this is the system that is most vulnerable to almost anything that impacts on the brain, including normal ageing. In the case of Alzheimer's, the deterioration is particularly marked. Other memory systems, such as semantic memory (the person's stored knowledge about the world), are much more resistant, and this can be used to help combat the effects of episodic memory loss. For example, people with dementia can be directly taught new semantic information that supports everyday functioning, such as the names of people they need to interact with frequently, or a set of directions to somewhere they need to visit regularly.

Another aspect of memory that is typically preserved in Alzheimer's is the cluster of memory systems sometimes called 'implicit memory', which includes procedural memory (memory for skills and routines). Implicit memory does not depend on recollecting anything; instead,

memory is demonstrated through action. This preserved element of memory can be used to help people with Alzheimer's relearn certain skills or manage them better. For example guided practice of everyday skills, such as washing, dressing or making a cup of tea, using a structured routine can help maintain the ability to carry out these tasks and so maintain independence.

The pattern of impairments seen in early Alzheimer's contrasts, for example, with that of fronto-temporal dementia. The temporal form of fronto-temporal dementia, often called semantic dementia, has only really been properly identified and explored in the last few years. As the name implies, impairment in semantic memory is the first symptom (Hodges *et al.*, 1999), while episodic memory is relatively preserved. In the frontal variant of fronto-temporal dementia, the earliest changes occur primarily in personality and behaviour.

Early detection and classification of dementia makes it possible to offer whatever help might maintain well-being and reduce later difficulties (Clare, 2002a). A series of studies carried out in Hull over the last decade (Moniz-Cook, Agar, Gibson *et al.*, 1998) provides strong evidence that a comprehensive early intervention programme that has been individualised for people and their families can have positive effects, both short and long term. This programme aimed to separate out neurological impairment from potentially

WHAT IS DEMENTIA?

Dementia has been defined as 'a clinical syndrome characterised by loss of function in multiple cognitive abilities...occurring in clear consciousness' (Whitehouse *et al.*, 1993); a syndrome of progressive cognitive impairment which does not result from an altered state of consciousness or other medical causes.

It is the progressive and ultimately widespread nature of the cognitive impairment that distinguishes dementia from brain injury and other neurological disorders, such as stroke. The dementia syndrome can result from various conditions, which are understood to reflect different underlying biological mechanisms and pathologies, although the value of diagnostic classification is disputed by some researchers and practitioners. The best-known form of dementia, and the most frequently diagnosed, is Alzheimer's disease; other forms of dementia include vascular dementia, fronto-temporal dementia, and Lewy body dementia.

Dementia affects predominantly, but not exclusively, older people. It is thought to affect about 5 per cent of all people over 65, and to increase in prevalence with advancing years so that 20 per cent of people over 80 are affected (Woods, 1996).

'socially malignant' attitudes (see Kitwood, 1997) at the time of diagnosis. It used interventions to prevent anxiety and depression and to promote interpersonal communication and physical health. Positive outcomes were seen in the following domains: aspects of cognition, depression, challenging behaviour, family burden, family stress, and the breakdown of care at home. Such an early intervention programme is a key contribution that clinical psychologists and neuropsychologists working within multidisciplinary teams can make.

The person-centred model

While a psychological understanding of the profile of cognitive strengths and weaknesses shown by the person with

dementia is essential, dementia is more than simply a matter of brain decay. People contribute a unique personality and a set of life experiences, coping resources and social networks.

Psychologists have taken the lead in emphasising that the way in which a person responds to the onset and progression of dementia is influenced by the coping resources of the person and the responses of those around them (Kitwood, 1997; Sabat, 2001). A positive, supportive environment can offset the effects of neurological impairment to some extent, while a negative environment or 'malignant social psychology' can exacerbate the effects and manifestations of impairment and result in excess disability (Reifler & Larson, 1990) – the person with dementia may appear more impaired than the degree of brain pathology would suggest ought to be the case. This understanding has led to the development of person-centred approaches to dementia care. These focus on understanding the experience of dementia in terms of the person's psychological responses and social context, and aim to tailor help and support to match individual needs. This contrasts strongly with the more traditional institutional approach to care.

Research from a phenomenological perspective has begun to provide an understanding of how the subjective experience of Alzheimer's, at least in the earlier stages, impacts on the individual (Clare, 2002b; Sabat, 2001). Receiving a diagnosis of Alzheimer's is a devastating experience, and the onset of dementia strikes at the core of self and close relationships. Memory problems can result in a sense of disconnection from one's past, and also make it difficult to participate socially. The balance of roles in previously equal partnerships shifts as one partner becomes the 'caregiver'. It is hard to

maintain a sense of identity, and it is difficult to continue activities that were previously enjoyed. Not surprisingly, a high proportion of people with Alzheimer's – as many as 40 per cent – experience depression, and levels of anxiety are also high (Ross *et al.*, 1998). Nevertheless, people with Alzheimer's typically adopt a range of coping strategies aimed at either maintaining or adjusting their sense of identity in the face of their progressive cognitive difficulties (Clare, 2002b).

For many people coping strategies include trying to hold on to a sense of normality by sticking to a routine or putting more effort into getting things done, and finding ways of compensating for changes by using practical strategies or taking medication. Some people find it helpful to adopt a fighting stance through finding out more about dementia, talking with others, volunteering for research, and making the most of aspects of life that can still be enjoyed. An important theme is the extent to which it is possible to maintain a sense of hope.

This improved understanding of how people adjust and cope is helping psychologists to develop interventions that can allow the person to overcome some of the effects of dementia-related disability. For example, counselling and support at the time of receiving a diagnosis are important (Husband, 2000); there is a growing consensus that people with early-stage dementia have a right to be informed about their diagnosis, even though this may sometimes be contrary to the preferences of the family (Maguire *et al.*, 1996). Other basic needs include the provision of information and assistance in planning for the future. Individual or group psychotherapy may help some people to deal with the emotional impact of dementia (Cheston, 1998), and others may benefit from support group membership (Yale, 1999) or cognitive-behavioural interventions to reduce depression (Teri *et al.*, 1997). Supportive or therapeutic interventions for family caregivers are also

vitaly important for the carer's own well-being and that of the care recipient (Marriott *et al.*, 2000).

Rehabilitation

A helpful way of thinking about psychological interventions – whether directed at the person with dementia, a family member, or both – is offered by the concept of rehabilitation. The World Health Organization model of disability distinguishes between organic impairment and engagement in activities or scope for social participation, and emphasises the importance of contextual factors. For people with dementia and their families, interventions can be directed at enhancing activity and participation, and optimising contextual resources. Both psychosocial (e.g. Bird, 2000; Moniz-Cook & Woods, 1997) and cognitive (e.g. Bird, 2001; Camp *et al.*, 2000; Clare *et al.*, 2000) rehabilitation have been used in this way.

In the early stages of Alzheimer's, when the main changes are in cognitive abilities such as memory, cognitive rehabilitation approaches are especially relevant (Clare & Woods, 2001). Cognitive rehabilitation aims to help people manage, bypass, reduce or come to terms with the effects of cognitive difficulties (Wilson, 1997). Research in early-stage Alzheimer's has shown that individual interventions can produce significant practical improvements in targeted areas. Usually these interventions address one of three domains:

- *Learning or relearning information*
Despite their memory impairments, people with dementia can learn and retain some new information, provided they are given appropriate support. Learning can be facilitated by techniques drawn from experimental psychological research and adapted for people with dementia, such as spaced retrieval, where material is recalled after

WEBLINKS

Alzheimer's Society: www.alzheimers.org.uk

Alzheimers Association (US) information database: www.alzheimers.org

Carers' website: www.carers.gov.uk

Dementia Advocacy and Support Network

International: www.dasinternational.org

living can help to maintain the ability to carry these out, and therefore prolong independent functioning (Zanetti *et al.*, 2001).

This rehabilitation approach harnesses the coping resources of people with dementia and allows them to take some active steps to help themselves. However, because dementia has very wide-ranging effects on the person and family, interventions based on cognitive rehabilitation need to be integrated within a comprehensive approach that considers the full range of needs that the person and family has at any given time.

Moving to residential care

As dementia progresses, the person and family may need support with negotiating a move to residential or nursing home care, or with ensuring well-being after such a move has been made. The majority of people with dementia live at home: only 20 to 30 per cent of people with dementia are in some form of long-term care. However, dementia is the most common reason for older people entering residential care, and about 40 to 50 per cent of residents in homes for older people (whether in residential homes, nursing homes or the few remaining NHS facilities) will have dementia.

Maintaining a sense of personal identity in an institutional setting is not easy, particularly for someone with cognitive impairments. Here again, psychologists can offer a rehabilitation-oriented approach. One way of trying to address the need to maintain a sense of self is to construct a life-story book that provides an account of the person's past experiences and conveys what kind of person they are. This helps staff to get to know the person, which in turn makes their caregiving task easier (Woods *et al.*, 1992). Similarly, a 'memory book' or 'memory wallet' containing personal information can be used to enhance communication.

Staff working in residential care settings themselves face significant difficulties. They often struggle in dealing with 'challenging behaviour' such as aggression, shouting and screaming, sometimes seen as symptoms of dementia. The standard response is to administer medication, typically major tranquilisers. Concern continues to grow regarding over-prescribing, in view of the limited efficacy and well-established side-effects of these drugs. In many cases it is possible through

careful psychological assessment and observation to identify the factors contributing to the behaviour, and thus to try to address the underlying causes or triggers (e.g. Moniz-Cook *et al.*, 2001; Moniz-Cook *et al.*, in press). Training staff to respond more appropriately results in improvements in attitudes and skills (Allan, 2001; Moniz-Cook, Agar, Silver *et al.*, 1998). Observational assessment methods such as dementia care mapping – an observational measure of the quality of person-centred care in formal care settings – provide powerful tools for assisting staff to enhance quality of care. The culture of the home, however, places constraints on what can be achieved by staff, so working at the organisational level is also essential (Lintern *et al.*, 2000).

Despite the difficulties with residential care, it is tempting when a person enters a residential home to think that at least the family will benefit and will now be less burdened and distressed. Unfortunately, the evidence is that family members of people with dementia admitted to residential homes are still distressed, although the nature and focus of the stress changes (Zarit & Whitlatch, 1993). Often families are keen to be involved in caring, yet it is very difficult to negotiate exactly how to remain involved. One promising approach has been the development of training materials to allow staff and families to come together and actually seek to understand the perspective of the other (Woods *et al.*, 2001). In homes where staff do work well with families, this has a major impact in terms of the quality of care for the people with dementia. Psychologists have an important contribution to make here.

Meeting the challenge of dementia

Despite advances in understanding the biological processes underlying dementia, the need for improved dementia care remains a major challenge for an enlightened society, in terms of the scale of the population affected, and the particular nature of the difficulties commonly encountered. Psychologists have been at the forefront of research and development contributing to improved care and support for people with dementia and their caregivers, and clinical psychologists working with older people have been instrumental in developing, implementing and disseminating approaches that offer hope and improved quality of life to all those involved.

gradually increasing intervals, and errorless learning, where the learning process is tailored to minimise errors during learning (Camp *et al.*, 2000; Clare *et al.*, 2000).

- *Learning to use a compensatory memory aid* With the help of behavioural techniques such as prompting and fading (giving cues and reminders, decreasing in frequency as the idea becomes familiar) people with dementia can learn to use memory aids. The use of aids such as a memory board or calendar can reduce the need to repeatedly question the caregiver (Clare *et al.*, 2000; Moniz-Cook, Agar, Gibson *et al.*, 1998a), and therefore reduce stress.
- *Maintaining skills and independence* Building on relatively preserved procedural memory, structured practice of specific skills and activities of daily

Two factors, apart from the evident need, may be related to the growth of this specialism in clinical psychology over the last 20 years. Firstly, there has been an extremely active and supportive BPS subsystem, Psychologists Special Interest Group for the Elderly, which through its newsletter and annual conference has given a sense of coherence and belonging to clinicians who more often than not worked single-handedly in the early years. Secondly, the requirement for all clinical psychologists in training to gain experience with older people and their supporters has led many trainees to consider this field as a possible area of work, and to appreciate the rewards and challenges it holds. There is concern that, with the growth in the number of training places, and a change in the requirements for placement experience, work with older people and people with

dementia will be downgraded in importance. This will require careful monitoring, to avoid implicit ageist attitudes reversing some of what that has been accomplished. There is a growing

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demand for psychological services for people with dementia and their caregivers, and the next few years will be crucial in maintaining a flow of clinical psychologists to meet this need. Psychology courses can help to achieve this by placing greater emphasis on the psychology of ageing and the psychological needs of older people at

both undergraduate and postgraduate level. The challenge of dementia touches the lives of all of us, and we cannot afford to ignore it.

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References

- Allan, K. (2001). *Communication and consultation: Exploring ways for staff to involve people with dementia in developing services*. Bristol: Policy Press.
- Baddeley, A.D., Bressi, S., Della Sala, S., Logie, R. & Spinnler, H. (1991). The decline of working memory in Alzheimer's disease. *Brain*, 114, 2521–2542.
- Bird, M. (2000). Psychosocial rehabilitation for problems arising from cognitive deficits in dementia. In R.D. Hill, L. Bäckman & A.S. Neely (Eds.) *Cognitive rehabilitation in old age*. Oxford: Oxford University Press.
- Bird, M. (2001). Behavioural difficulties and cue recall of adaptive behaviour in dementia. In L. Clare & R.T. Woods (Eds.) *Cognitive rehabilitation in dementia. A special issue of Neuropsychological Rehabilitation*. Hove: Psychology Press.
- Brandt, J. & Rich, J.B. (1995). Memory disorders in the dementias. In A.D. Baddeley, B.A. Wilson & F.N. Watts (Eds.) *Handbook of memory disorders*. Chichester: Wiley.
- Camp, C.J., Bird, M.J. & Cherry, K.E. (2000). Retrieval strategies as a rehabilitation aid for cognitive loss in pathological aging. In R.D. Hill, L. Bäckman & A.S. Neely (Eds.) *Cognitive rehabilitation in old age*. Oxford: Oxford University Press.
- Cheston, R. (1998). Psychotherapeutic work with people with dementia. *British Journal of Medical Psychology*, 71, 211–231.
- Clare, L. (2002a). Assessment and intervention in Alzheimer's disease. In A.D. Baddeley, B.A. Wilson & M.D. Kopelman (Eds.) *Handbook of memory disorders* (2nd edn). Chichester: Wiley.
- Clare, L. (2002b). We'll fight it as long as we can: Coping with the onset of Alzheimer's disease. *Ageing and Mental Health*, 6, 139–148.
- Clare, L., Wilson, B.A., Carter, G., Gosses, A., Breen, K. & Hodges, J.R. (2000). Intervening with everyday memory problems in early Alzheimer's disease: An errorless learning approach. *Journal of Clinical and Experimental Neuropsychology*, 22, 132–146.
- Clare, L. & Woods, R.T. (Eds.) (2001). *Cognitive rehabilitation in dementia. A special issue of Neuropsychological Rehabilitation*. Hove: Psychology Press.
- Hodges, J.R., Patterson, K., Ward, R., Garrard, P., Bak, T., Perry, R. et al. (1999). The differentiation of semantic dementia and frontal lobe dementia (temporal and frontal variants of frontotemporal dementia) from early Alzheimer's disease. *Neuropsychology*, 13, 31–40.
- Husband, H.J. (2000). Diagnostic disclosure in dementia: An opportunity for intervention? *International Journal of Geriatric Psychiatry*, 15, 544–547.
- Kitwood, T. (1997). *Dementia reconsidered: The person comes first*. Buckingham: Open University Press.
- Lintner, T., Woods, B. & Phair, L. (2000). Training is not enough to change care practice. *Journal of Dementia Care*, 8, 15–17.
- Maguire, C.P., Kirby, M., Coen, R., Coakley, D., Lawlor, B.A. & O'Neill, D. (1996). Family members' attitudes toward telling the patient with Alzheimer's disease their diagnosis. *British Medical Journal*, 313, 529–530.
- Marriott, A., Donaldson, T., Tarrier, N. & Burns, A. (2000). Effectiveness of cognitive-behavioural family intervention in reducing the burden of care in carers of patients with Alzheimer's disease. *British Journal of Psychiatry*, 176, 57–62.
- Moniz-Cook, E., Agar, S., Gibson, G., Win, T. & Wang, M. (1998). A preliminary study of the effects of early intervention with people with dementia and their families in a memory clinic. *Ageing and Mental Health*, 2, 199–211.
- Moniz-Cook, E., Agar, S., Silver, M., Woods, R., Wang, M., Elston, C. et al. (1998). Can staff training reduce behavioural problems in residential care for the elderly mentally ill? *International Journal of Geriatric Psychiatry*, 13, 149–158.
- Moniz-Cook, E., Stokes, G. & Agar, S. (in press). Difficult behaviour and dementia in nursing homes. *Clinical Psychology and Psychotherapy*.
- Moniz-Cook, E. & Woods, R.T. (1997). The role of memory clinics and psychosocial intervention in the early stages of dementia. *International Journal of Geriatric Psychiatry*, 12, 1143–1145.
- Moniz-Cook, E., Woods, R.T. & Richards, K. (2001). Functional analysis of challenging behaviour in dementia: The role of superstition. *International Journal of Geriatric Psychiatry*, 16, 45–56.
- Morris, R.G. (1996). The neuropsychology of Alzheimer's disease and related dementias. In R.T. Woods (Ed.) *Handbook of the clinical psychology of ageing*. Chichester: Wiley.
- Morris, R.G. & McKiernan, F. (1994). Neuropsychological investigations of dementia. In A. Burns & R. Levy (Eds.) *Dementia*. London: Chapman & Hall.
- Reifer, B.V. & Larson, E. (1990). Excess disability in dementia of the Alzheimer's type. In E. Light & B.D. Lebowitz (Eds.) *Alzheimer's disease treatment and family stress*. New York: Hemisphere.
- Ross, L.K., Arnsberger, P. & Fox, P.J. (1998). The relationship between cognitive functioning and disease severity with depression in dementia of the Alzheimer type. *Ageing and Mental Health*, 2, 319–327.
- Sabat, S. (2001). *The experience of Alzheimer's disease: Life through a tangled veil*. Oxford: Blackwell.
- Teri, L., Logsdon, R.G., Umoto, J. & McCurry, S.M. (1997). Behavioural treatment of depression in dementia patients. *Journals of Gerontology Series B, Psychological Sciences and Social Sciences*, 52, 159–166.
- Whitehouse, P.J., Lerner, A. & Hedera, P. (1993). Dementia. In K.M. Heilman & E. Valenstein (Eds.) *Clinical neuropsychology*. Oxford: Oxford University Press.
- Wilson, B.A. (1997). Cognitive rehabilitation: How it is and how it might be. *Journal of the International Neuropsychological Society*, 3, 487–496.
- Woods, R.T. (1996). Mental health problems in late life. In R.T. Woods (Ed.) *Handbook of the clinical psychology of ageing*. Chichester: Wiley.
- Woods, R.T., Portnoy, S., Head, D. & Jones, G. (1992). Reminiscence and life-review with persons with dementia. In G. Jones & B. Miesen (Eds.) *Care-giving in dementia*. (pp.137–161). London: Routledge.
- Woods, R.T., Ross, H., Keady, J. & Wenger, G.C. (2001). *Partners in care*. Bangor: Dementia Services Development Centre Wales.
- Yale, R. (1999). Support groups and other services for individuals with early-stage Alzheimer's disease. *Generations*, 23(3), 57–61.
- Zanetti, O., Zanieri, G., Giovanni, G.D., de Vreese, L.P., Pezzini, A., Metitieri, T. et al. (2001). Effectiveness of procedural memory stimulation in mild Alzheimer's disease patients. In L. Clare & R.T. Woods (Eds.) *Cognitive rehabilitation in dementia. A special issue of Neuropsychological Rehabilitation*. Hove: Psychology Press.
- Zarit, S.H. & Whitlatch, C.J. (1993). The effects of placement in nursing homes on family caregivers. *Irish Journal of Psychology*, 14, 25–37.