



## editorial

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### The role of dementia training programmes in reducing care-giver burden

Family care-givers play a vital role in the support of people with dementia. In addition to opportunity costs, care-giving has been linked to a wide range of negative outcomes, including psychological disturbance, physical health problems, relationship changes and social activity restrictions (Donaldson *et al*, 1997). Carers identify access to information and training as an essential requirement in their struggle to continue in the care-giving role (Blackwell *et al*, 1992). To what extent are these training needs currently met? Despite an undoubted demand, few training initiatives exist for informal carers, or indeed for formal home care staff, a deficiency which has prompted a European Union project to develop a training package for family carers of elderly people with dementia (O'Donovan *et al*, 1997; Turner & Street, 1999).

Does the provision of training actually reduce the burden of caring for a family member with dementia? Although most qualitative studies report that carers find intervention programmes to be helpful, the results of controlled trials have not produced consistent evidence of benefit (Brodaty, 1992). This may be due to the significant methodological differences between studies, notably in the content and aims of the training programmes.

#### Programme content

The content of carer support programmes provided by voluntary and statutory organisations, as well as in clinical trials, is highly variable, and is determined mainly by the resources available to the providers and the training needs of carers. These needs will change with the progression of dementia (Turner & Street, 1999). Following diagnosis, carers need information about the nature of the illness and the availability of services, as well as emotional support. Subsequently, advice will be required on the practical and emotional aspects of caring, including coping with loss and the need to develop or maintain their interests outside of the caring role. Training programmes can broadly be divided into those which provide education and skills training, and programmes comprised of comprehensive multifaceted interventions.

#### Educational programmes

A fundamental component of a dementia training programme is the provision of information on the

medical, psychosocial and legal aspects of dementia, planning for future loss of the patient's cognitive and functional abilities, and the promotion of specific skills, such as behaviour modification, communication, patient stimulation, and basic daily living skills such as lifting and bathing (Brodaty, 1992). Does an increased understanding of dementia improve a carer's ability to adjust to the physical and psychological demands of caring? Graham *et al* (1997) have demonstrated that knowledge of dementia has a complex effect on carers' psychological health. Family care-givers who were more knowledgeable considered themselves to be more confident and competent in dementia care, had reduced expectations of their dependants' abilities, and were less likely to be depressed. On the negative side, knowledge was associated with increased anxiety levels, perhaps by increasing the carers' anticipation of loss.

Although increasing carer knowledge has been reported to be beneficial (Chiverton & Caine, 1989), two recent studies have failed to demonstrate that education programmes produce a positive impact on care-givers. Brodaty *et al* (1994) designed a six-session training programme focused on the provision of information on the disease process, stress management and the management of disruptive behaviours in a group setting. Carers who completed the programme showed no reduction in psychological burden compared with controls. More recently, Coen *et al* (1999) assessed the impact of an eight-session carer education and support programme. Although carers' knowledge of dementia increased, the programme had no significant impact on their quality of life or psychological burden.

#### Comprehensive programmes

In addition to education, comprehensive programmes typically offer psychological support to the carer, including opportunities for ventilation, mutual support, counselling and stress management, as well as strategies to develop family, community and professional support systems (Brodaty, 1992).

In one of the first controlled trials of care-giver training, Brodaty & Gresham (1989) assessed the impact of a highly structured and intensive 10-day residential



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programme. The intervention consisted of didactic education, group therapy and extended family therapy sessions for carers, in conjunction with memory retaining, reminiscence therapy and physical and psychiatric review for patients. Continued support was offered in the form of telephone conference calls over a 12-month period. At follow-up the carers and patients in the training programme had significantly lower psychological distress and lower rates of institutionalisation, respectively, compared with controls.

Ostwald *et al* (1999) designed and assessed a multi-dimensional training programme, the Minnesota Family Workshop (MFW), which focuses on the carer's personal resources for care-giving (knowledge, skills and belief in one's own ability) as well as external care-giving resources, especially the organisation of the rest of the family to support the care-giver. A central theme of the 14-hour training programme is that a thorough understanding of the patients' cognitive and functional abilities helps carers design appropriate care-giving strategies. For example, it helps care-givers understand how much and what kind of direction to provide, what level of performance to expect, and how to prompt and communicate effectively. At follow-up, patients in the MFW showed no significant decrease in disruptive behaviours compared with controls. However, carers in the training programme experienced less distress in response to such behaviours, whereas carers in the waiting list group experienced a marked rise in burden scores over the same period.

### Programme aims

While many studies have examined the impact of interventions on carer well-being and psychological morbidity, some have focused on more specific outcomes, such as institutionalisation (Mittelman *et al*, 1996), or clearly defined carer or patient symptoms. For example, Teri *et al* (1997) demonstrated that teaching carers to use behavioural treatments emphasising either pleasant events with patients or problem-solving skills reduced depressive symptoms in both the dementia patients and the carers themselves. Hinchliffe *et al* (1995) designed individual care plans, including training in behavioural management techniques, pharmacotherapy and social support, targeted at specific problem behaviours, including aggression and urinary incontinence. The comprehensive intervention programme successfully reduced patient behavioural disturbances, and also improved carer mental health. Unfortunately, the benefits of multifaceted interventions appear to diminish in more advanced dementia. Brodaty & Gresham (1989) and Hinchliffe *et al* (1995) both found that for waiting list carers and their dependants, the introduction of successful (but delayed) programmes failed to produce the expected benefits.

### Conclusions

Dementia training programmes aim to reduce the burden of care-giving and to indirectly help dementia sufferers,

perhaps by reducing behavioural disturbances or delaying institutionalisation. Education alone appears to be of limited value, as it has little impact on carer well-being or behavioural symptoms. The intervention programmes which have reported positive results are mostly comprehensive and multidimensional. The resources required for such programmes are beyond those available to most providers, and there is an urgent need to identify the core information and skills requirements of dementia carers, and the most cost-effective means of organising and delivering training programmes. The available research evidence suggests that training programmes should be sufficiently flexible to identify and respond to the needs of individual carers, target specific carer or patient symptoms, be introduced at an early stage in the illness process, and include a component of continuing support. Such programmes may play a valuable role in reducing the enormous burden of caring for a family member with dementia.

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