Cognitive rehabilitation for people with dementia: what is it and does it work?

Alex Bahar-Fuchs, Aleksandra Kudlicka and Linda Clare describe how cognitive rehabilitation can be used as part of an enablement approach to support people with dementia, and their families, maintain better quality of life and independence.

A defining feature of dementia is the presence of cognitive or behavioural symptoms that are severe enough to interfere with a person’s ability to independently carry out their usual activities of daily living (McKhann et al 2011).

Within the World Health Organisation’s framework, the cognitive and/or behavioural impairments of the person with dementia lead to disability in relation to the person’s capacity to perform specific daily activities, and to participation restriction in the context of everyday life and roles (WHO 1998).

A biopsychosocial framework of dementia (Clare et al 2012a) emphasises that the underlying brain pathology does not solely determine the overall level of functioning. Even when underlying impairment cannot be addressed, some barriers to activity and participation can be removed, and overall experience of dementia improved, by appropriate management of personal, social and environmental factors.

Along with an increasing emphasis on the primary and secondary prevention of dementia, there is growing recognition of dementia as a chronic health condition (WHO 2012) with the implication that those with a diagnosis and their families require ongoing support in managing the effects of the illness. This recognition also underscores the importance of applying person-centred principles to the support and care of people with dementia, to maximise their agency and autonomy, dignity and well-being.

An enablement approach to dementia care

In line with a person-centred approach to dementia care we are advocating that an enablement philosophy should serve as the organising framework for the care and support of people with dementia (Clare 2016). Rather than focusing on disability, an enablement approach focuses on what the person with a disability can do with appropriate support, and encourages engagement, shared decision-making and facilitation of factors that promote optimal participation in meaningful life activities in context.

Cognitive rehabilitation

Cognitive rehabilitation (CR) is an individualised, person-centered approach, in which people with cognitive impairments, their close support network and healthcare professionals work collaboratively to identify personally-meaningful and achievable goals couched in everyday activities, and then use evidence-based strategies (compensatory, restorative, or both) in pursuit of these goals. CR is distinct from the general Cognitive Stimulation approach (Woods et al 2012) described in the article on p12) in that it addresses individual needs and challenges to enhance independence in day-to-day activities, and from cognitive training in that it does not aim to improve cognitive abilities per se (Clare et al 2003a).

CR has mainly evolved from work with people with acquired brain injuries (ABI), such as traumatic brain injuries, and stroke, and was designed to help people with cognitive impairments re-integrate into their previous life context (Wilson 1997). However, as argued previously (Clare et al 2003b) the principles that underpin CR for people with ABI are just as applicable when it comes to people with dementia.

Cognitive rehabilitation in practice

Unlike the case for people with ABI, within the context of dementia caused by progressive neurodegenerative conditions like Alzheimer’s disease (AD), goals will inevitably need to change to accommodate further decline in function as the disease progresses. Ideally, CR should be offered soon after the diagnosis, when dementia is of mild severity, as early intervention provides an opportunity for advanced planning, and to capitalise on the person’s residual cognitive strengths and relatively circumscribed functional limitations.

When applied early, CR may also contribute to a sense of hope to the affected person and their family members that something can be done to allow them to live better with dementia.

With disease progression, maintaining basic practical skills and engagement in conversation may provide a focus when working with individuals with moderate dementia. In the later stages the focus may shift to enabling expression of preferences, with an emphasis on optimising well-being and maintaining dignity.

Drawing on the results of a comprehensive assessment of the person’s cognitive and behavioural functioning, their psychological adjustment and coping styles, and the support available to them, the CR specialist will typically work with the person with dementia and close others to identify a number of potentially achievable goals related to their day-to-day function.

Importantly, goals will generally not be framed in terms of a cognitive process (eg, ‘I want to improve my memory and attention’), but in terms of relevant daily activities (eg, ‘I will only discuss socially appropriate matters with the friends we meet with for lunch once a fortnight’, or ‘I will check upon delivery that all the groceries arrived as ordered through the online delivery service’).

The CR specialist can be any healthcare professional with suitable clinical training, qualifications, and experience in brain-behaviour relationships and intervention delivery, and may or may not be the person doing the actual routine work with the affected person and their family. In Australia, clinical neuropsychologists are uniquely positioned to act as CR specialists but other professionals, including occupational therapists, clinical psychologists, and speech-language therapists may also have the relevant training and experience to engage in CR work, possibly with the support or supervision of an experienced neuropsychologist.

The person with dementia and members of the close support network will then be guided to use a range of evidence-based techniques that have been demonstrated in carefully designed studies to support learning and re-learning of information among people with dementia (see ‘Learning with dementia’ p38).

What is the evidence?

To determine whether or not there is compelling evidence for or against a particular treatment or intervention it is...
Learning with dementia

Evidence from experimental studies shows that, when provided with appropriate support, people with early stage or mild dementia can learn or relearn relevant information, as well as adapt their behaviour and develop new routines, skills and habits. Cognitive rehabilitation (CR) builds on this evidence and exploits this knowledge to identify the most relevant methods of helping the person with dementia better manage everyday activities.

For example, when people with dementia learn new information while limiting their opportunity to make memory errors they sometimes recall information better than they do through trial and error – an approach known as errorless learning (Haslam et al 2011).

Another technique that has been successfully used to support learning in people with dementia is known as spaced retrieval. The simple principle underlying this technique is that when the time interval between the learning and subsequent recalling of information is very short (eg 30 seconds), and increases systematically in fixed increments of time, there is a greater chance that information will create a stronger trace in the person’s long-term memory store. Using spaced retrieval, we and others have demonstrated that people with mild dementia recalled face-name associations for up to nine months (Clare et al 1999; Clare et al 2003a).

Importantly, people with dementia respond differently to various evidence-based techniques, and a CR therapist will assist the person and their family to identify the technique(s) that are most helpful for the individual in question.

Although much of the work on CR to date has been carried out on people with mild Alzheimer’s disease (AD) dementia or mixed AD and vascular-type dementia, principles of CR have also been applied in intervention studies targeting people with other forms of dementia, including semantic dementia (eg Savage et al 2013), and work is currently underway with people with Parkinson’s disease (Hindle et al 2018).

generally best to perform a systematic review of individual high-quality studies investigating the treatment (usually randomly randomised controlled trials or well-designed single case studies) and to then summarise the results using statistical techniques (meta-analysis).

Comprehensive systematic reviews conducted by the authors first in 2001 (Clare et al 2001) and most recently updated in 2013 (Bahar-Fuchs et al 2013) identified only a single trial that met the definition of CR, so it was not possible to perform a meta-analysis. A careful look at the literature revealed that a confusion regarding terms and definitions prevails in the professional community, and that studies that describe cognitive training and cognitive stimulation are sometimes referred to as ‘cognitive rehabilitation’ by study authors, while lacking some of its defining components.

We and others (Hampstead et al 2014; Lampit et al 2014) have argued that increasing the methodological standard of trials in this field, including improving the clarity around definitions of different cognition-focused intervention approaches, is a priority. To this end, a group of international experts in this area of research, led by the first author, recently formed CIDER (Cognitive Interventions Design, Evaluation and Reporting), which aims to publish guidelines to improve the methodological quality of trials in this area (Bahar-Fuchs et al 2014; Bahar-Fuchs et al 2016). (We expect to have a CIDER website available in 2017).

The only trial that met our inclusion criteria (Clare et al 2010) was a single-blind randomised controlled trial (RCT) in which 69 participants with mild-moderate dementia (Alzheimer’s disease or mixed Alzheimer’s disease and vascular dementia) were allocated to eight weeks of either CR, relaxation therapy (RT), or to a no-treatment (NT) condition.

The trial found that relative to the RT and NT conditions, immediately after the intervention participants in the CR condition showed improvements in self-rated performance and satisfaction with relation to goals they had set for themselves.

Participants in the CR condition were also more satisfied with their memory performance than participants in the no-treatment condition at the six-month follow-up assessment. Caregivers of participants in the CR and RT conditions reported improvements in their social relationships relative to caregivers of participants in the no-treatment condition.

The GREAT study

A large multi-site follow-up to that study, led by Professor Linda Clare (co-author here) is currently underway in the UK (Clare et al 2013). The GREAT study (short title: Living Well with Memory Difficulties, www.exeter.ac.uk/great) involves individuals with Alzheimer’s disease or mixed Alzheimer’s disease and vascular dementia. These people are randomly allocated to either a Treatment as Usual (TAU) condition or to 10-weeks of CR over three months followed by four maintenance sessions over six months.

CR intervention focuses on addressing individual therapy goals, with components on compensatory strategies, practical techniques for learning new information, practice in maintaining attention and concentration, and techniques for stress management.

The study began in 2012, and data collection is expected to be completed by December 2016. Results are expected to be available in 2017. If the pilot trial findings are confirmed, GREAT will provide definitive evidence in support of CR as a clinically-effective and cost-effective intervention for people with mild-moderate Alzheimer’s disease. It will pave the way for a wider implementation of this intervention approach in the healthcare system in the UK, and possibly in other countries, including Australia.

Challenges and opportunities

CR provides a useful conceptual framework for support of people with dementia and their families; it opens an opportunity for delaying the progression of functional disability by better management of cognitive deficits and so may help to maintain better quality of life and independence.

As the evidence for efficacy gradually develops, various challenges and opportunities may need to be considered for its full potential to be realised. Among these are the role of emerging technologies, applicability of CR to the context of dementia prevention, the development of agreed upon outcome measures, and addressing prevailing unhelpful views regarding the ‘point’ of rehabilitation for people with dementia.

Emerging technologies

Emerging technologies already play an increasingly central role in rehabilitation of people with various needs. This trend will no doubt continue and change the way rehabilitation goals are achieved while remaining true to the fundamental principles of being function-led and individually tailored.

Already digital technology is used
extensively to support a range of compensatory strategies (eg, reminders, organising activities, recording important information, etc.) While computerised cognitive training to date has been criticised for being abstract and removed from real-world activities, the emergence of function-led and individually-tailored virtual reality applications has the potential to challenge existing distinctions between cognitive training and cognitive rehabilitation (Parsons et al 2015; Garcia-Betances et al 2015).

Dementia prevention
Cognitive rehabilitation as an intervention strategy need not be restricted only to people with established cognitive and functional impairments. The enablement philosophy at the heart of CR can and should be extended to individuals at risk of dementia, including people with mild cognitive impairment, as well as cognitively healthy adults with lifestyle, health-related or even genetic vulnerability for dementia.

While cognitively healthy older adults and people diagnosed with mild cognitive impairment do not usually exhibit significant functional disability, many individuals in these groups will nonetheless identify functional areas in which they would like to do things more effectively or in a way that might facilitate the development of ‘cognitive reserve’ – broadly defined as the individual’s ability to continue performing daily tasks successfully despite accumulating brain pathology (Stern 2002). For example, healthy older adults with a tendency to misplace objects might be assisted to develop habits that reduce the likelihood of losing personal belongings, especially given that it is likely to be more difficult to form such habits in the face of cognitive impairment.

Outcome measures
An important challenge in evaluating the efficacy of highly individualised psychosocial interventions, including CR, is that there typically is not a single agreed upon or objective ‘metric’ against which efficacy is evaluated. Also, because the outcomes of interest are behavioural and/or psychological, and because CR does not target a biological or cognitive process per se, biomarkers (including cognitive performance), often regarded as key endpoints in other intervention approaches, are seen as less relevant in studies of CR efficacy.

One solution to overcoming difficulties with outcome measures in the context of individualised interventions such as CR is the use of measures of goal attainment. Goal attainment scaling as the Goal Attainment Scaling (Kiresuk et al 1968; Malec 1999), the Canadian Occupational Performance Measure (Law et al 2005), or the Bangor Goal Setting Interview (Clare et al 2012b) allow for progress in relation to individualised goals to be converted into standardised scores, which is an important methodological feature in group studies.

Such an approach, of course, is not without its limitations in the context of trials in which participants and caregivers are not blinded to the intervention they receive, and researchers must continue exploring ways to improve outcomes measurement in studies of CR.

Finally, for CR and any other intervention approach based on principles of enablement to be successfully integrated into the care of people with dementia, more work needs to be done to understand how to shift views, perspectives and practices to be more aligned with an enablement framework.

Shifting attitudes and beliefs
Changing longstanding attitudes held by some members of the healthcare community, and indeed often by people with dementia and their families – that often focus primarily on the need for a ‘cure’ rather than on the possibility of living better with dementia – is possibly among the most significant challenges in the field.

Shifting attitudes and beliefs is often a slow process. A coordinated approach in which scientists work collaboratively with advocacy groups, government, industry and even the media is required to bring about wide-scale changes in world-views.

Such changes are critical if enablement approaches such as cognitive rehabilitation are to be truly integrated into the way we work with people with dementia and their families, and with older adults more broadly.

References


Trial HALTs unnecessary use of antipsychotics

Preliminary results from the HALT Project show that the majority of people with dementia in aged care homes who are prescribed antipsychotic medications to control BPSD do not need them. Tiffany Jessop reports

The Halting Antipsychotic use in Long Term Care (HALT) Project is an Australian study, running since 2014, aiming to reduce the use of antipsychotic medication in long-term care residents with behavioural and psychological symptoms associated with dementia (BPSD).

Inappropriate prescribing of antipsychotics for people with dementia is common, particularly for those living in care homes where multiple residents may present with distressed behaviour. As a result, GPs and geriatricians may feel pressure to prescribe psychotropic medications, including antipsychotics, in response to BPSD in care home residents – despite best practice guidelines suggesting non-pharmacological approaches should be tried before resorting to medication and then only for three months before reviewing.

The tight regulations around the use of these medications are due to the significant risks and side effects associated with their use in older people. These include dizziness, accelerated cognitive decline, falls, pneumonia, stroke and death. The modest potential benefit of these medications needs to be weighed carefully against these risks in each individual and they should be prescribed with caution.

One antipsychotic, Risperidone, is currently indicated for psychiatric symptoms, or persistent agitation or aggression in Alzheimer’s disease but not other dementias. Despite this, we still see antipsychotics administered in response to behaviours for which there is no evidence of benefit such as wandering, calling out and delirium, in residents with comorbid vascular conditions or other forms of dementia, and for long periods without review. Until the HALT intervention, participants had been taking their current course of antipsychotics for an average of two years.

We are now heading into the final three months of the trial, involving 140 residents across 23 NSW care facilities. Preliminary results indicate that the HALT deprescribing intervention successfully eliminated antipsychotic medications from the treatment plan in the majority of participants.

Initially, over 90% of study participants ceased antipsychotic medication, but not all remained off the medication during the follow-up period. Fourteen recommended regular antipsychotic medication within three months, and a further 10 within six months and two (to date) before the final visit at 12 months (a total of 21% of the sample who originally ceased the antipsychotic medication).

Importantly, preliminary analyses show behavioural and psychological symptoms remain stable up to six and 12 months after deprescribing for all participants, regardless of whether an antipsychotic was restarted or never ceased after deprescribing commenced.

We have almost completed 12-month follow-up data collection from participating residents and final results will be available at the end of this year.

Controlled deprescribing

The reduction in antipsychotic use was achieved through controlled deprescribing involving community pharmacists, facility staff, participants’ GPs and family members. Long-term care facility nurses (HALT champions) were also trained to recognise potential causes of BPSD and encourage the use of non-pharmacological and person-centred approaches, including environmental modifications, to manage symptoms.

Participants were assessed for neuropsychiatric symptoms, agitation, cognition, activities of daily living and quality of life twice before deprescribing and then three months, six months and 12 months after deprescribing started.

Feedback from HALT champions

The research team has also spent a substantial amount of time talking with the HALT champions to understand how the project was received by staff and management and what, if any, sustainable impact it has had on the residents as well as the facilities. The HALT champions are a critical component of the project. These champions are, for the most part,