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For all who work with people with dementia
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Everyone can dance

Also inside this issue:
- Massively successful MOOC
- Cognitive stimulation
- Is involuntary confinement too easy?
- Words can hurt
Cognitive Stimulation Therapy: a pilot Australian adaptation

Daniella Kanareck, Suzanne Mathie, Natalie Narunsky, Helen McCaskie, Justine Finlay and Brian Draper report on their pilot study of an Australian adaptation of the Cognitive Stimulation Therapy (CST) program, developed in the UK to improve cognition and social functioning in people with mild to moderate dementia.

Dementia affects over a quarter of a million Australians and currently treatments have limited efficacy (AIEHW 2012). Studies have shown that Cognitive Stimulation Therapy (CST) improves cognitive functioning, quality of life and the well-being of people with dementia in a cost-effective manner and without the use of pharmacotherapy (Spector et al 2003).

Background of CST
CST was devised from a systematic literature review that identifies the most effective non-pharmacological therapies for dementia. Its hypothesis is that consistent stimulation of cognitive skills such as memory, language and attention can potentially be useful in slowing the rate of cognitive decline. CST is a structured multisensory intervention aimed at improving cognition and social functioning, offering a "range of enjoyable activities providing general stimulation for thinking, concentration and memory usually in a social setting, such as a small group" (Woods et al 2012).

The National Institute for Health and Clinical Excellence, which provides national guidance and advice to improve health and social care in the UK, recommends the use of structured group cognitive stimulation programs for people with mild to moderate dementia (NICE 2006). CST studies and groups have been conducted globally, and the International CST Centre website provides an extensive list of participating countries, www.ucl.ac.uk/international-cognitive-stimulation-therapy/countries.

Dr Aimee Spector, Senior Lecturer in Clinical Psychology at University College London, was the lead researcher of the original CST trial in 2001. She co-authored the CST training manuals and has led CST training courses. CST can be facilitated by people working in the area of dementia care, such as care workers, occupational therapists or nurses in residential homes, hospitals or community day centres. There are two structured manuals published for CST group leaders: Making a difference (Spector et al 2006) provides the themes and structure for the initial 14 sessions and Making a difference 2 (Aguirre et al 2012) for the 24 Maintenance CST (MCST) sessions. This second manual comes with a DVD showing filmed examples of sessions.

Listed in the box below are the 18 key principles essential for facilitators to understand and put into practice when directing each session. The themes are elicited through activities outlined in the manual such as physical games, sound, 'my life', food, current affairs, art discussion, associated word discussions, being creative, categorising objects, orientation, using money, number, word and team games. The facilitators prepare activities aimed at promoting these themes, creating a fun and enjoyable environment that targets maintaining and...
strengthening the participants' social and cognitive skills whilst building upon their skill mastery and social interaction.

**Australian adaptation**

In 2013, the Aged Care Psychiatry (ACP) Department, Eastern Suburbs Mental Health Service, Sydney, conducted a pilot study of an Australian adaptation of CST and MCST programs. The aim was to ascertain if CST is adaptable to Australian conditions; what changes would be required to ensure cultural applicability, and to propose guidelines for translation of knowledge about CST for local dementia services.

We conducted a non-randomised pilot study of CST and MCST modelled on the UK program, funded by a grant from the Dementia Collaborative Research Centre: Assessment and Better Care (DCRC: ABC), UNSW Australia. The adaptation was evaluated from session to session, as well as at the completion of both CST and MCST programs.

**Points considered for adaptation**

Based on the advice of Dr Spector, the *Making a difference* 2 manual was used for both initial CST and MCST programs, as all relevant material from the first manual and additional information was featured in the second manual. The manual provided the framework to deliver the program in a consistent and routine manner. Within this framework there was flexibility to use material selected by the group to meet the aims of each session theme.

We retained the themes from the UK manual, but added Australiana such as music, art, food, geographical landmarks and advertisements in place of UK equivalents. For example, UK content such as Bovril, maps of the London Underground and British locations were replaced with Australian content including Vegemite, pictures of native flora and fauna and famous Australian faces. Full details of the adaptation will be available in an Australian manual now being developed to accompany the MCST manual *Making a difference 2* and due for release in 2015.

The material was presented in various multisensory formats - for example: cues for discussion; debate and reminiscence; team games such as sound bingo and trivial pursuit; and creative challenges such as cooking.

Feedback about the content changes came from consumers and carers from Alzheimer’s Australia’s Consumer Dementia Research Network (CDRN). Ethics approval was obtained from South Eastern Sydney Local Health District Human Resources Ethics Committee (HREC).

**Training**

ACH Group, Adelaide (a not-for-profit aged care service provider) has offered CST in a range of settings since 2006, with CST principles incorporated into its social groups in community settings since 2009. Lenore de la Perelle, Manager of ACH Group’s Dementia Learning and Development Unit, provided a one-day CST training workshop for our research team. Suzanne Mathie, a member of our research team, also attended Dr Spector’s CST training course in London in 2012. This information was incorporated into the planning of each session.

**Recruitment**

Participants in our pilot study were outpatients attending the ACP Department, aged 60 years and over with mild to moderate DSM-IV dementia. They were required to have lived in Australia for at least 10 years, have adequate mobility, vision and hearing, be able to communicate and understand English and provide written informed consent. Exclusion criteria included behaviours thought likely to disrupt the group, having a learning disability, and a current diagnosis of severe depression. Carers were English-speaking family or friends identified by the participant who were able to provide informed written consent. Our sample group consisted of three males and five females ranging in age from 69-85 years. Three of the participants were born overseas. Seven were diagnosed with Alzheimer’s disease and one with frontotemporal dementia.

**Assessments**

In preparation for a possible multi-site Australian randomised controlled trial (RCT) study, we also administered assessments:

- **Mood:** Cornell Scale for Depression in Dementia, CSDD (Alexopoulos et al 1988); scores range from 0 to 38, with higher scores indicating more severe depressive symptoms.

- **Behaviour:** Neuropsychiatric Inventory, NPI (Cummings et al 1994). In this study we used only the severity and care distress rating scales. The severity scores range from 0 to 36 and the care distress scores range from 0 to 48, with higher scores indicating greater behavioural concerns.

- **Quality of life:** Quality of Life – Alzheimer’s disease, QoL-AD (Logsdon et al 1999); scores range from 13 to 52, with higher scores indicating better quality of life.

- **Functional ability:** Functional Status Questionnaire, FSQ (Jette et al 1986); scores physical, psychological, social and role functions. Scores indicate areas that require further investigation. As the FSQ included functional aspects not applicable to this cohort, it was replaced with the Disability Assessment for Dementia, DAD (Gauthier et al 1994) after the initial set of assessments.

- **Cognition:** Mini Mental State Examination, MMSE (Folstein et al 1975); scores range from 0 to 30 with higher scores indicating better cognition.

These assessments were completed at the start of the initial CST program and at the conclusion of both the initial and final MCST program.
Structure of the CST and MCST sessions

CST aims to provide cognitive stimulation through active engagement within the group, encouraging new ideas and thoughts using reminiscence and previously retained information. CST commences with a seven-week program consisting of 14 x 45-minute sessions. This is followed by the 24-week MCST program. This pilot study took place in the ACP Department, a venue known to the participants and their carers.

Each session was co-facilitated by two members of the research team (occupational therapist, social worker or mental health nurse). After each session verbal feedback was gathered from participants according to the structure suggested in the manual. The facilitators also monitored the progress of each participant using the 'Monitoring Progress Form' from the CST manual Making a Difference 2.

General observations

During the consenting process participants were informed about the structure and purpose of CST. However, it became evident that the participants had difficulty in retaining this information. Consequently, as part of the orientation segment in each session, participants took turns in reading aloud the aims of CST to the group. This highlighted the importance of providing repetition throughout the program to strengthen understanding and reinforce learning.

The routine and structure of the sessions appeared to help each member of the group develop their own role and become more confident. Participants were encouraged to contribute at their own level. For example, one became the scribe, one enjoyed being the 'choo master' for the group song and another helped make the tea and serve the food during the tea break. Throughout the program the participants encouraged one another and developed a sense of camaraderie.

The facilitators focused on each participant's strengths, life experiences and preferences within the group setting. This enabled the content to be person-centred. For example, when preparing the session for 'My life occupations,' the facilitators researched the participants' occupations to generate group discussion.

Participants commented that the materials used were suitable for Australians. They were equally responsive to global concepts and universal knowledge as they were to the Australian content – both of which prompted discussion about life experiences and generated opinions. Additionally, the inclusion of local content as noted above encouraged participants to interact and bond over shared experiences.

Practical considerations

- The tea break segment enhanced participant conversation; fostered socialisation; encouraged dialogue around each other's interests and how they had spent their week. Having a tea break before the start of each session helped limit disruptions of late arrivals.
- One participant did not return for the maintenance program due to separation anxiety at being parted from her carer. She also had a hearing impairment. This reinforced the significance of adhering to the selection criteria to meet the goals of the CST program.
- It is necessary to provide a good location with easy access for participants, with an appropriate sized room, ideally including a toilet located nearby – otherwise a group facilitator had to leave the group in the midst of a session to escort participants to a toilet.
- CST was costly to run in a hospital setting due to staff wages and costs associated with transporting participants to and from the group.

Results

The results of the CST course are presented in Table 1 (above). Cognition and Neuropsychiatric Inventory (NPI) carer distress scores did not change, but it was pleasing to note that quality of life improved, severity of behaviour reduced and depression scores declined. However, with this small sample size the results should be interpreted with caution.

Observed results: participants

- Carers and facilitators anecdotally noted reduced apathy as the program provided routine and a sense of purpose.
- The group provided an

<table>
<thead>
<tr>
<th>Table 1: Assessment of participants' cognition, mood and quality of life: Effects of 7-week CST program</th>
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<tbody>
<tr>
<td>Scale</td>
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<tr>
<td>Mean Mini Mental State Examination Score (0-30)</td>
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<tr>
<td>Mean Participant-Rated Cornell Scale for Depression in Dementia (0-38)</td>
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<tr>
<td>Mean Carer-Rated Cornell Scale for Depression in Dementia (0-38)</td>
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<tr>
<td>Mean Participant-Rated Quality of Life - Alzheimer's Disease (13-52)</td>
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<tr>
<td>Mean Carer-Rated Quality of Life - Alzheimer's Disease (13-52)</td>
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<tr>
<td>Mean Neuropsychiatric Inventory - severity score (0-36)</td>
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<tr>
<td>Mean Neuropsychiatric Inventory - carer distress score (0-48)</td>
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Food slogans and adverts were used in the sessions, with participants matching slogans with brands and then singing the advertising jingles.

'Household treasures' encouraged reminiscence and generated discussion among participants about how times had changed.

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Opportunity for participants to socialise and obtain peer support in a setting where dementia was a commonality as opposed to a barrier. Improved mood and confidence was observed by the facilitators.

- Reintroducing topics such as art, money and travel; activities such as cooking and team games as well as visual prompts to aid discussion, all helped reawaken participants’ former interests and skills.
- Examples of feedback from the participants include:
  - “It must be useful because it makes me think.”
  - “It gives me ideas to improve what I am doing.”
  - “We can talk to each other, it is not embarrassing.”

Observed results: carers
Carers welcomed an early intervention program and were keen to be involved in this pilot CST program. They ensured the participants attended the weekly sessions, and perceived that the CST program provided a sense of purpose and an opportunity for structured carer respite. Each carer welcomed the regular contact via a weekly phone call from a group facilitator. This gave them information about the progression of the program, including additional carer support and education. Midway through MCST, carers attended an information session and afternoon tea. It gave them an opportunity to gain a better understanding of CST and allowed them to ask group facilitators and each other questions. They were able to give feedback about their positive and negative observations. At the conclusion of the CST program, the carers said that the groups had been beneficial in the life of the participants and perceived there would be a void in their lives when it concluded.

Life after CST
In line with the CST key principles in maintaining the strengths and abilities of each individual and ensuring a person-centred approach, facilitators worked with the participants (and their carers) to identify services or activities best suited to them post-CST. Recommendations included attending a men’s group; University of the Third Age; day centres; exercise classes; and visits from a volunteer.

Limitations of this pilot adaptation
This pilot study set out to assess an Australian adaption of the CST program and determine the feasibility of selected assessment tools to measure five domains (cognition, behaviour, mood, functional ability and quality of life). We were able to effectively trial assessment tools, yet the small sample size limited the scope to provide any valid analysis of the data.

While we believe the general principles of adaptation will be relevant to other cultural groups (such as Culturally and Linguistically Diverse (CALD) and Aboriginal and Torres Strait Islander) in Australia, we have no data to support this.

Conclusion
CST was well received by our participants who had mild to moderate dementia. This pilot study proved to be an effective Australian adaption of the CST material. We have now commenced the groundwork in developing Australian guidelines to complement the MCST manual. In order to determine the cost-effectiveness of CST in Australia, a multisite RCT replicating the UK study should be implemented.

Further work being undertaken in CST
As stated earlier, we are developing guidelines for an Australian adaptation to complement the MCST manual, planned for release mid-2015. These will be available on the DCRC website at www.dementiaresearch.org.au. The Whiddon Group, (which has a number of community and residential facilities throughout NSW) has requested a CST training course to be facilitated by our team in February 2015.

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References

Daniella Kanareck (social worker), Suzanne Mathie (clinical nurse consultant), Natalie Narusky (occupational therapist), Justine Finlay (social worker) and Professor Brian Draper (Old Age Psychiatrist and Director) are from the Aged Care Psychiatry Department, Eastern Suburbs Mental Health Services, Sydney; Helen McCaskie is a dementia consultant at the Dementia Behaviour Management Advisory Service HammondCare, NSW. Professor Draper is also Conjoint Professor, School of Psychology, UNSW Australia. For more information, contact: Daniella.Kanareck@sesiah.health.nsw.gov.au.

The authors. Above, from left: Suzanne Mathie, Daniella Kanareck, Natalie Narusky and Helen McCaskie. Right, from top: Prof Brian Draper and Justine Finlay.