

Cognitive stimulation therapy

A New Zealand pilot

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Te Pou
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Executive summary

Introduction

Dementia is a neurodegenerative disorder associated with high levels of disability and dependence. In 2011 there was an estimated 48,182 New Zealanders with dementia – 1.1 per cent of the total New Zealand population (Alzheimers New Zealand, 2011). By 2050 there will be an estimated 147,359 New Zealanders with dementia (2.6 per cent of the population) and an estimated 41,008 new cases each year. Most people with dementia will at some stage require complex care support in the community. Currently most services to people with dementia and their families are focused on providing education about the illness and support for people to stay at home.

The Ministry of Health's recently published *Dementia Care Framework* (Ministry of Health 2013) provides guidance for district health boards (DHBs) to plan their dementia services and develop dementia care pathways for a better coordination of dementia services within each DHB. In this framework Cognitive Stimulation Therapy (CST) is one of two specific treatments recommended as good practice for dementia.

Cognitive stimulation therapy (CST) is a structured group treatment developed for people with mild to moderate dementia. The therapy consists of 14 sessions with a range of activities and discussions aimed at general enhancement of cognitive and social functioning. The sessions actively engage people with dementia, while providing an optimal learning environment, and the social benefits of being part of a group.

The overall aim of this project was to pilot CST groups in both community and residential care settings to assess its acceptability in the New Zealand context.

To evaluate the pilots, a research project was funded by Te Pou and commissioned through Auckland Uniservices. The project commenced in March and was completed August 2014.

Method

The project evaluation utilised a mixed methods approach. An independent research assistant collected data on demographics, diagnosis and outcome measures on enrolled participants. This included quality of life, cognitive function measures, self-reported depressive symptoms (facility participants only), and family outcomes (for example, carer burden and self-reported health status).

Informant interviews using a semi-structured interview guide were undertaken to assess perceptions of CST from participants receiving CST, their families and practitioners delivering the programme in both the community and residential care setting.

Three CST groups, two in the community and one in an aged residential care facility were delivered between March and June 2014. A total of 18 participants completed the programme. The two community groups had seven participants in each group recruited from the Alzheimers Auckland Charitable Trust support group and had a diagnosis of mild to moderate dementia. An aged care facility located in West Auckland replicated the entry criteria and group size as the community group.

The sessions followed the *CST Treatment Manual* developed by Spector et al. (2006). This involved the group meeting for one hour twice a week for seven weeks. The 14 sessions included topics such as music, food, current affairs, creativity and word and number games, and were conducted by a CST practitioner.

Key findings

This pilot study showed that CST is an acceptable psychological therapy for older people with a clinical diagnosis of mild to moderate dementia. It is able to be delivered relatively easily in both community and residential care settings.

Positive effect on mood

The reduction in depression symptomatology amongst older people residing in an aged residential care facility following a course of CST was statistically significant. The mean baseline Geriatric Depression Scale (GDS)-15 score was 12 (high level of depressive symptoms). The mean post-CST GDS 15 score was 6.7.

Improved memory

There was an average increase of 0.3 points on the Mini Mental State Examination (MMSE) and 2.0 points on the Alzheimer's disease Assessment Scale-Cognitive behaviour (ADAS-Cog) in all participants. Although these results were not statistically significant the amount of change was comparable to the results identified in the recent Cochrane review of CST (Woods et al., 2012).

Improved quality of life

While individuals receiving treatment did not report improved quality of life themselves, families and caregivers reported positive changes in participants' quality of life.

Acceptability, appropriateness and effectiveness of CST

Qualitative data was collected in relation to participants' perceptions of the acceptability, appropriateness and effectiveness of the CST programme. Three main themes were identified by participants; group dynamics and the two social aspects of the group. The social engagement of the group was seen by most as important as the activities undertaken by the group. Being in the company of others with similar memory problems provided both a supportive environment and a place where they felt relaxed and comfortable. The impact of CST became apparent for participants who, after attending CST for several weeks, reported varying improvements in memory. Some described this as significant, and others did not.

From the family and CST practitioners' perspectives, real time benefits were noted within two to three sessions. This group described the term 'switch on' phenomenon, as they saw changes in their loved ones who had been disengaged, and at times aggressive and socially inept. Following CST sessions they noticed participants had new-found confidence, capabilities and vastly improved communication skills.

From the facilitators' perspectives improving the uptake of CST in the future requires financial consideration in relation to transport and access to information technology. Providing transport for CST attendees would alleviate some of the burden that families experienced in this study. Access to technological aids would allow both facilitators and participants a 'vehicle' to access resources during sessions.

Conclusions and recommendations

This pilot study has shown that very few modifications are required to deliver CST programmes in New Zealand aged care settings. This outcome demonstrates that CST delivered in its original format supports successful implementation in the New Zealand context.

Recommendation 1: Development of a CST training and accreditation programme in NZ

CST practitioners have an important role in translating this evidence-based therapy into practice. Developing a workforce skilled in CST is a priority in order to ensure best practice. Alongside workforce development in CST, the establishment of a web-based portal for peer support and ongoing continuing education for trained CST practitioners needs urgent attention.

Recommendation 2: DHB Dementia Care Pathway to include CST as a treatment option

That district health boards' Dementia Care Pathways for the management of people with cognitive impairment/dementia should include CST as a treatment option following diagnosis.

Recommendation 3: Establish maintenance CST programs

As a result of the successful outcomes of participants enrolled in this pilot study, both Alzheimer's Auckland and a Radius Care aged residential care facility have elected to deliver the 28 weeks CST maintenance programme. Funding is being sought to undertake a 28-week follow-up to explore the effect and dose response required to maintain the benefits of CST.

Introduction

Dementia is a neurodegenerative disorder associated with high levels of disability and dependence. Most people with dementia will at some stage require complex care support in the community. In 2011 there was an estimated 48,182 New Zealanders with dementia – 1.1% of the total New Zealand population (Alzheimers New Zealand, 2011). By 2050 there will be an estimated 147,359 New Zealanders with dementia (2.6% of the population) and an estimated 41,008 new cases each year. Currently most services provided to people with dementia and their families are about educating them about the illness and supporting them to remain in their own homes as long as possible.

The Ministry of Health recognises the need for improvement in dementia care in New Zealand and recently published the *New Zealand Framework for Dementia Care* (Ministry of Health, 2013). This framework provides guidance for the 20 district health boards (DHBs) to plan their dementia services and develop dementia care pathways for a better coordination of dementia services within each DHB. In this framework Cognitive Stimulation Therapy (CST) is one of the two specific treatments recommended as good practice for dementia. CST can be one of the ways to maintain cognitive function and quality of life in the community, as an additional strategy to the services already provided.

Te Pou sponsored this project which commenced in March 2014 and concluded in August 2014.

Cognitive Stimulation Therapy (CST): Background

Cognitive stimulation is defined as “engagement in a range of activities and discussions (usually in a group) aimed at general enhancement of cognitive and social functioning” (Clare & Woods, 2004, p. 387).

It is different from cognitive rehabilitation and cognitive training. Clare and Woods (2004) defined cognitive rehabilitation as an individualised approach where personally relevant goals are identified, and the therapist works with the person and his/her family to devise strategies to address these goals and provide cognitive training. CST is guided practice on a set of standard tasks designed to reflect particular cognitive functions with a range of difficulty levels to suit the individual’s level of ability.

CST has its basis in Reality Orientation Therapy (Spector, Orrell, Davies & Woods, 2001). Reality orientation therapy was initially developed to reduce confusion in rehabilitating war veterans, who had developed mental disorders related to their experiences but were not necessarily diagnosed with dementia (Spector, Davies, Woods & Orrell, 2000; Patton, 2006). Its emphasis is on refocusing people with dementia to reality, with frequent reorientation of the person with dementia through aspects of life such as the date and time (Baines, Saxby & Ehler, 1987). Elements of Reminiscence Therapy were also included in the development of CST (Yuill & Hollis, 2010). Reminiscence Therapy involves the discussion of past events, relationships, and experiences with the intent of raising mood and improving cognition (Spector et al., 2000; Cotelli, Manenti & Zanetti, 2012).

CST is a structured and manualised group treatment specifically developed for people with mild to moderate dementia. It involves 14 or more sessions of themed activities (Spector, Thorgrimsen, Woods & Orrell, 2006). The key principles and structure of CST are outlined in Tables 1 and 2. They were designed to run twice a week over a seven-week period. Sessions aim to actively stimulate and engage people with dementia, while providing an optimal learning environment and the social benefits of a group. The effects of CST appear to be of a

comparable size to those reported with the currently available anti-dementia drugs (Prince, Bryce, Ferri, 2011). CST was developed in the UK and has been adopted in 23 countries including one CST site in New Zealand.

Table 1: *Principles of CST*

Key Principles	
• Person-centred	• Respect
• Involvement	• Inclusion
• Choice	• Fun
• Options rather than facts	• Using reminiscence
• Using the senses – multi-sensory stimulation	• Always have something to look at, touch or feel
• Maximising potential	• Building and strengthening behaviours

Table 2: *Structure of CST Sessions*

Structure of Cognitive Therapy Sessions		
Introductions:	Welcome	(10 minutes)
	Group name	
	Theme song	
	Orientation discussion (using whiteboard)	
	Current affairs	
	Refreshments	
Main Activity:	Level A – Seeking opinion, social interaction	(25 minutes)
	Level B – Less complex, relaxed exercise	
Finally:	Thanks for attending and contribution	(10 minutes)
	Theme song	
	Reminders re next session and content	
	Farewells	

CST: Evidence for effectiveness

The original CST program consisted of 14 sessions with four foci: the senses, remembering the past, people and objects and found positive trends in cognition and mood (Spector et al., 2000).

A further UK study in 2003 involving 281 people with dementia (Mini-Mental State Examination [MMSE] 10 to 24) showed a series of CST sessions (twice a week for seven weeks) resulted in significant improvements in measures of cognition, including the MMSE (Spector et al., 2003). The *World Alzheimer Report* reviewed the evidence on cognitive stimulation therapy in patients with mild to moderate dementia and found the overall efficacy of cognitive stimulation was consistently positive. In all 11 CST studies showed statistically and clinically significant treatment effects. Efficacy in the delivery of the program either by group or one to one intervention also had a positive effect.

The effect sizes associated with the intervention, for the ADAS-Cog and the MMSE, are similar to those seen for acetylcholinesterase inhibitor drugs, and are apparent for mild as well as moderate dementia. There does also seem to be evidence of efficacy over and above acetylcholinesterase inhibitor medication effects (Prince, Bryce and Ferri, 2011).

A cost effectiveness study found that cognitive stimulation therapy for people with dementia may be more cost-effective than usual treatment (Knapp et al., 2006). According to the NICE dementia guidelines “the evidence suggests that in the UK, providing cognitive stimulation therapy alongside usual care for people with mild to moderate dementia in care homes and day-care centres is likely to be more cost effective than usual care alone (National Institute for Health and Clinical Excellence, 2006).

A recent Cochrane review concludes that cognitive stimulation programmes can benefit people with mild to moderate dementia over and above any medication effects (Woods, Aguirre, Spector & Orrell, 2012). However, the authors noted that further, larger randomised controlled trials and research on the effects of longer-term cognitive stimulation programmes are needed.

CST and anti-dementia medication

According to the NICE dementia guideline (2006) there is now reasonable evidence to support the use of cognitive stimulation approaches with people with mild to moderate dementia. Importantly, there are now indications of improvements in quality of life to accompany the well-established modest improvements identified in cognitive function. The importance of appropriate, respectful, person-centred care attitudes in the implementation of these approaches has been highlighted in the largest, and most successful, CST trial to date. Cognitive stimulation appears to add to the effects of donepezil in both mild and moderate Alzheimer’s disease.

CST in New Zealand

We undertook an informal sector survey through the National Dementia Cooperative (NDC) in July 2013. The NDC has approximately 600 members from a wide range of occupations and backgrounds including medical, nursing, allied health, carers, managers and academics in New Zealand.

The survey found that Hawke’s Bay District Health Board (DHB) was the only service delivering CST to patients with mild to moderate dementia. The other findings were:

- Capital Coast DHB¹, Hutt Valley DHB and Southern DHB were in the process of putting forward a business case; however, due to financial constraints they were having difficulty progressing their proposals
- the Alzheimer's Societies in Waikato and Canterbury DHB were planning to incorporate elements of CST into their group treatment for people with dementia
- Southern DHB has a cognitive rehabilitation group which runs for nine weeks – no information was available on the content of group sessions but there is a fundamental difference between cognitive rehabilitation and cognitive stimulation
- Midcentral DHB performed a cost analysis modelling exercise on CST, which found support for saving in residential care beds.

¹ Since the survey Capital Coast DHB has started to offer CST and the Mental Health Services for Older People at Waitemata DHB also trialled CST for their existing patients in the latter part of 2013.

About the CST Pilot Study

The aim of this study was to pilot CST groups in a community and an aged residential care setting in Auckland and to evaluate its feasibility. The intention is that knowledge gained from this project can be translated into the wider dementia sector in New Zealand.

Project objectives

The specific project objectives were to:

- pilot CST in two community settings
- evaluate the pilot programme in terms of its feasibility and client outcomes
- evaluate the adaptation of the CST programme in the New Zealand context
- translate the knowledge gained from the pilot programme
- develop a CST service delivery model for the dementia sector in New Zealand.

In New Zealand CST groups are currently delivered by specialist mental health services in two or three DHBs. This project is the first New Zealand study investigating the feasibility of delivering CST in community and aged care settings.

Delivering CST within the New Zealand health system

The *New Zealand Framework for Dementia Care* (Ministry of Health, 2013) is underpinned by four principals:

- (i) person-centred and people-directed approach
- (ii) accessible and proactive services
- (iii) integrated services
- (iv) highest possible standard of care.

The elements of CST described in earlier sections are consistent with the person-centred and people-directed approach. In addition ensuring this evidenced-based treatment is available for people with dementia is aligned with the other principles of the framework. The framework also emphasises workforce education and training, which will be discussed in a later section.

Rising to the Challenge: The Mental Health and Addiction Service Development Plan 2012-2017 includes a section on service delivery recommendations for older people (Ministry of Health, 2012). The development plan recommends that DHBs ensure older people with dementia can access specialist mental health expertise when needed. This specialist expertise will be delivered as an integrated part of a wider health sector response to the needs of people with dementia, aimed at supporting people to live well within the community of their choice. For those older people in aged residential care, DHBs may provide specialist mental health nurses and/or support workers to work alongside residential support staff for a brief period.

This pilot project involved delivering CST in an aged residential care facility, in the community to people living in their own homes. Knowledge gained from this project may benefit other DHBs that wish to make this treatment more accessible. The *Mental Health and Addiction Service Development Plan* (2012) also includes monitoring access to evidence-informed psychological therapies for mental health and addiction issues in

primary care as one of the key performance indicators. As a number of dementia care pathways in New Zealand will be primary care-focused, this CST pilot project has potential to improve psychological treatment for dementia in primary care.

Method

Preparatory activities

In preparation for the CST groups in Auckland, members of the research team undertook a site visit to Hawke’s Bay DHB in November 2013. Appendix A describes the outcomes of this visit.

Settings and participants

Three CST groups (two in the community and one in an aged residential care facility) were established and run between March and June 2014 in Auckland. Each group had six to seven participants. The participants in the community were recruited from members of the Alzheimer’s Auckland Charitable Trust. The groups were held in a hired community centre in West Auckland. For the aged residential care facility, residents from Taupaki an aged care facility in West Auckland, were recruited. The CST programme was delivered in the facility.

Participants in both treatment settings were purposively selected by the clinicians based on the recommendations by Aguirre and Orrell (2010) that included:

- 1. diagnosis of dementia
- 2. the person can have a ‘meaningful’ conversation.
- 3. the person can hear well enough to participate in a small group discussion.
- 4. the person’s vision is good enough to see most pictures.
- 5. the person is likely to remain in a group for 45 minutes.

Approval for this project was prospectively sought and obtained from the Ministry of Health’s Health and Disability Ethics Committee (Ethics Ref: 13/STH/167). Due to the presence of cognitive impairment, assent was obtained from participants, with informed consent obtained from their next of kin.

CST group structure and content

The delivery of CST followed the treatment manual developed by Spector et al. (2006). Each group met twice a week for seven weeks and each session lasted 50 minutes. The themes covered in the 14 sessions are shown in Table 3.

Table 3: Themes of CST Sessions

Themes of CST Sessions	
1. Physical games	8. Being creative
2. Sound	9. Categorising objects
3. Childhood	10. Orientation
4. Food	11. Using money
5. Current affairs	12. Number games
6. Faces/scenes	13. Word games
7. Word association	14. Team quiz

CST Practitioners: Training:

The research team utilised a train-the-trainer approach for practitioners involved in the delivery of CST in this project.

- (i) Community groups: An experienced occupational therapist, who had previously delivered CST to people with intellectual disabilities and participated in the Hawke's Bay DHB site visit, delivered the two community groups with the support of a volunteer worker.
- (ii) Aged residential care group: A nurse manager and an enrolled nurse, with no previous experience with CST, underwent the following training prior to running the CST group:
 - 1. Reading the material on the U.K. CST website (<http://www.cstdementia.com>)
 - 2. Reading the treatment manual (Spector et al., 2006)
 - 3. Watching the DVD (included in the maintenance treatment manual) that illustrates CST groups in action (Aguirre et al., 2012)
 - 4. Observing and participating in one CST group run by the occupational therapist.

CST Group observation by project team

A member of the project team observed one community group session and one aged residential care group session. The aim of these observations was to ensure the CST protocol was strictly followed. The project leads also provided support and guidance for the CST practitioners where needed between CST sessions.

Data collection

An independent research assistant collected data on basic demographic characteristics, diagnosis, and pre- and post-outcome measures from participants and their families. The quantitative measures (cognitive functioning, quality of life and carer burden) used in this pilot project are consistent with those used in previous CST research (Woods et al, 2012). The participant and family measures used are described below.

Participants (both community and aged residential care facility)

- (i) Folstein Mini Mental State Examination (MMSE) (Folstein, Folstein & McHugh, 1975)

The MMSE is a brief instrument with 30 items that is used to screen for cognitive impairment. It is also commonly used to estimate the severity of cognitive impairment at any given point in time and to follow the course of cognitive changes in an individual over time. Scores on the MMSE range from 0-30. Broadly speaking, a score of 20-26 indicates some cognitive impairment; 10-19 moderate to severe cognitive impairment, and below 10 very severe cognitive impairment.

- (ii) Alzheimer's Disease Assessment Scale – cognitive subscale (ADAS-cog) (Mohs et al, 1997)

ADAS-cog is the most popular cognitive testing instrument used in clinical trials of anti-dementia medication. It consists of 11 tasks measuring disturbances in memory, language, praxis, attention and other cognitive abilities which are often referred to as the core symptoms of Alzheimer Disease with scores range from 0 to 70. More severe cognitive impairment is reflected in higher total ADAS-cog score.

- (iii) Quality of Life-Alzheimer's Disease (QOL-AD) – Version for the person with dementia (Logsdon, Gibbons, McCurry & Teri, 1999)

The QOL-AD is a brief 13 item instrument designed to assess the quality of life of people with dementia. The QOL-AD assesses the person's relationships with friends and family, concerns about finances, physical condition, mood, and an overall assessment of life quality. Each item is rated on a four point scale, with 1 being poor and 4 being excellent. Total scores range from 13 to 52. Patients with MMSE scores of 10 or higher can usually complete it without any difficulties.

Participants (aged residential care facility only)

- (iv) Geriatric Depression Scale – 15 items (GDS-15) (Sheikh, Yesavage & Brink, 1986)

The GDS-15 consists of a series of 15 questions. It is a widely used instrument for the screening of depression in older people. It can be administered as a self-rating or observer-rating scale. In this project it was self-rated by the participants. A score of less than five indicates that the person is unlikely to have a depressive illness.

Families (both community and aged residential care facility)

- (v) Quality of Life-Alzheimer's Disease (QOL-AD) – Version for the family member or caregiver

This part of QOL-AD obtains ratings from the family/staff of the person with dementia. A 13 item questionnaire, total scores range from 13 to 52.

Families (community only)

- (vi) Caregiver Burden Inventory (CBI) (Novak & Guest, 1989)

The CBI is a 24 item multi-dimensional instrument that measures the impact of burden on caregivers. The five dimensions are: time dependency, development, physical health, emotional health and social relationships. Each item ranges from 0 (not at all descriptive) to 4 (very descriptive). Total burden scores ranged from 0 to 96. A higher score indicates greater caregiver burden.

- (vii) Medical Outcomes Study 12-Item Short-Form Health Survey (SF-12) (Ware, Kosinski & Keller, 1996)

The SF-12 is a widely used generic health status instrument to assess health related quality of life. It was developed to describe mental and physical health status of adults, and to measure health care intervention outcomes. The SF-12 items allow the calculation of the physical component summary (PCS) and mental component summary (MCS). A higher score on the SF-12 reflects a better quality of life.

Statistical analysis

The Statistical Package for the Social Sciences (SPSS) Version 20 was used for quantitative data analysis. Paired t-tests (2-sided) were used for comparing the pre- and post-outcome measures, with a statistical significance level set at 0.05.

Qualitative evaluation

Semi-structured interviews were conducted by an independent researcher to assess the perception of the CST programme from various perspectives of participants, family and CST facilitators. All interviews were conducted using a semi-structured interview guide (Appendices B, C, D). The main topics discussed during the interview related to what went well, what didn't, and how the programme might be improved. Views of the participants and their families were sought. Facilitators' and other key stakeholders' views were also obtained. All interviews were conducted within two weeks of the final CST session.

Interviews were audio-recorded and transcribed verbatim. The qualitative data were analysed using a general inductive approach (Thomas, 2006). The transcripts were read individually and then evaluated by two independent researchers with relevant categories identified. Further in-depth analysis was undertaken by refining and grouping the categories into main themes. All data were anonymised and pseudonyms were used in reporting the qualitative results.

Attached in Appendix E is a summary of the costs incurred for delivering the two CST groups in the community provided by Alzheimer's Auckland Charitable Trust.

Findings

This section reports the results from the pilot CST groups using both quantitative and qualitative methods. It outlines the modifications made to CST for the New Zealand context. It then describes the outcomes for the CST pilot participants in terms of outcomes and experiences of the programme. These findings are used to assess acceptability, appropriateness and effectiveness of the CST. Three case studies are included to illustrate the effectiveness of CST from individuals' perspectives.

The specific project objectives were to:

- pilot CST in two community settings
- evaluate the pilot programme in terms of its feasibility and client outcomes
- evaluate the adaptation of the CST programme in the New Zealand context
- translate the knowledge gained from the pilot programme

CST Modifications in the New Zealand context

Using the framework developed by Stirman, Miller, Toder and Calloway (2013), the following describes how CST was adapted for use in the two treatment settings in this pilot project.

Content

The CST practitioners in this pilot project strictly adhered to the manual published by the CST developers including the theme song (Spector et al., 2006). During the Hawke's Bay site visit, we learnt that participants did not enjoy the theme song and excluded from the CST programme. Prior to commencing this pilot project, the project team decided a theme song would be optional: participants and CST practitioners would decide as a group whether there would be a group theme song. This anticipated modification would be applied to both CST settings in this project. Interestingly, all three CST groups in this project preferred the theme song.

The other modification involved a CST practitioner who utilised Google search information during sessions as clarification of information and additional stimulation for the participants; for example, the dates of significant historical events such as world wars and natural disasters.

There was no other content modification departing from the intervention or integrating another approach.

Context

The pilot project did not involve require any contextual modification in terms of its format, setting, personnel and population.

Training

CST can be administered by a range of non-professional and professional staff working in dementia care, such as care workers, occupational therapists, psychologists or nurses. The delivery of CST in previous international studies has involved practitioners attending a one-day training workshop. It has been suggested that attending CST training teaches practitioners to apply the key principles during CST, encouraging its use in a standardised, person-centred and effective way.

CST practitioners involved in this project did not attend a one-day training workshop as in previous CST research in the UK. The training for the CST practitioners in this pilot study was different from the suggested training by the UK developers (refer to page 14). The “train the trainer” model was used for novice practitioners.

The Cochrane review on cognitive stimulation suggested that the implementation of cognitive stimulation in real-life settings needs to be addressed (Wood et al., 2012). In particular, the question is whether or not the results obtained by those who attend brief training in the methods or make use of one of the treatment manuals, or both, are comparable to those obtained in the context of research studies and RCTs. Training issues that arose during following the pilot CST programs are addressed in a later section.

Comprehensive CST training manuals can be purchased from Hawker Publications (<http://www.careinfo.org/books/>). The manuals include the key principles of CST, a session-by-session plan, details of the equipment needed and ways of monitoring progress (Spector et al., 2006).

Evaluation

Participants

Thirteen people (nine males and four females) with dementia participated in two CST groups in the community. One of the community participants decided not to return after the first session, preferring to continue with his hobbies at home. This participant was excluded from subsequent analysis. Seven people (two males and five females) participated in one CST group in the aged residential care facility. One of the aged residential care participants died during the programme. This participant was excluded from subsequent analysis.

The mean ages (75.7 vs 81.6) and MMSEs at baseline (23.2 vs 21.1) of the community and residential care participants were similar with no statistical difference. Therefore, results were analysed as one group and such grouping of analysis is consistent with previous CST trials where dementia subtypes and locality of the groups were combined. A total of 18 participants completed a course of 14 CST sessions.

Outcomes

Table 4 shows the results of the outcome measures at baseline and completion of CST.

Table 4: Outcome Measures at Baseline and Post-CST

Outcome measures	N	Baseline	Post-CST	Change from baseline	Standard deviation	p-value (2-tailed)
ADAS-Cog	18	33.2	31.2	-2.0	5.5	0.16
MMSE	18	22.6	22.9	+0.3	2.2	0.60
QOL-AD (self-reported)	18	36.8	34.8	-2.0	5.8	0.16
QOL-AD (Family/staff-reported) ¹	17	31.7	35.2	+3.5	9.3	0.14
SF12 ²	11	94.6	93.1	-1.5	16.4	0.76
CBI ²	11	34.0	35.3	+1.3	17.2	0.81
GDS-15 ³	6	12.2	6.7	-5.5	4.1	0.02*

ADAS-Cog: Alzheimer's Disease Assessment Scale-cognitive subscale (Mohs et al, 1997); MMSE: Mini Mental State Examination (Folstein, Folstein & McHugh, 1975); QOL-AD: Quality of Life-Alzheimer's Disease (Logsdon, Gibbons, McCurry & Teri, 1999); SF12: 12-Item Short-Form Health Survey (Ware, Kosinski & Keller, 1996); CBI: Caregiver Burden Inventory (CBI) (Novak & Guest, 1989); GDS: Geriatric Depression Scale – 15 items (Sheikh, Yesavage & Brink, 1986)

¹ One participant lived alone and a family member is not available to complete this part of QOL-AD

² Completed only by families of participants living in the community

³ Completed only by participants living in the aged residential care facility

* Significant at 5% level.

Qualitative results

Participants and family members were interviewed to gain a more in-depth understanding of the acceptability, appropriateness and effectiveness of CST in aged care community and residential settings. Participants (all community-dwelling people) and their families of the two CST groups run by the Alzheimer's Auckland Charitable Trust participated in the qualitative evaluation. A total of nine participants (six males and three females) and eight family members (six spouses and two siblings) were interviewed. In addition three CST practitioners were interviewed.

Participants

Participants' experiences of attending the CST sessions can be explained in the following three main themes : group activity sessions, group dynamics and socialisation.

(i) Group Activity Sessions

The emergence of this theme arose as participants described in more detail the CST sessions including the structured activities. It explores the activities as its relevance to the New Zealand context as well as provides insights into the effects it had on stimulating brain activity.

Likes and dislikes

All the participants reported they got something special out of the sessions. For three participants it was being able to talk about the past:

I really liked talking about things from the past (Jane) ...reflecting on the past (Sue); while Colin talked about different things especially the past (Colin).

Several other participants were surprised just how much they enjoyed doing activities they would normally not join in as Mary explains; "I enjoyed it all even the sporty things as I'm not normally a sporty person, while Alex found that I liked what was going on, and answering the things the correct way felt good", while John found it brought out the "competitive side of himself".

Opportunities to listen to other members of groups ideas and views were considered one of the main highlights. Helen describes this as lively discussions; *I was looking for something to do. I loved the association and hearing other people's views and ideas.*

For other participants some activities were not so enjoyable. For example, Colin didn't like the painting activity while another participant didn't see the point in the picture activity.

Stimulation

One of the most interesting and unexpected findings was the notion of feeling stimulated. Being stimulated provided participants with a sense of achievement and made them feel excited, an emotion that many had not been able to experience recently. Several participants succinctly described how this happened for one of the male participants in their group.

...by the third or fourth session it was like a switch went off and he became more vocal. He was like that all the time after this (Colin).

For others they could describe clearly the stimulating effects of CST sessions despite their recognised memory loss.

I wasn't in control of it yet it sparked something in my mind (Jane).

They would throw something on the table and we would run with it and your brain would be going (Sue).

I used to feel so good while I was there [CST session] and afterwards. I would go home and think about what we had been talking about (Colin).

Feeling this way made participants want to continue with the group and not want to return to prior feelings of hopelessness. John summarised what the majority of the group reported; *I no longer want to sit around at home like I did. I couldn't handle it. I want the group to go on forever.*

(ii) Group Dynamics

Without exception participants spoke about how as a group of strangers they bonded within several CST sessions which had a positive effect on the group as a whole. The group processes provided a settling in period, a safe place to feel supported, empathy for members, and a way to evaluate individual improvements.

Settling in

The majority of participants described how they were unsure what to expect from attending the group and several stated they went only to please their families. They discussed how the CST practitioners running the sessions ensured that each person was given equal opportunities to answer questions and explained in detail how the initial group activities provided a way to get to know each other better:

The facilitator [CST practitioner] and some of the others participants made sure the ones in the group who wanted to answer all the questions were asked nicely to give others a chance (Colin).

We were all strangers but within two to three sessions we were laughing and having fun (Grant).

Supportive environment

As participants became more comfortable with each other and got to know their names they noticed how supportive they became to each other, even in little ways. They were able to recall that although they were all

there because of memory problems, no one brought up this issue. The group provided a non-threatening environment which had a positive effect on participants.

They didn't talk about the disease, I felt good about that (Jane) and I didn't associate my problem with the group and we didn't spend time talking about it (Grant).

Lex described this aptly; *We were doing this jigsaw puzzle and it had all different shapes. We were all trying to do it with not much luck but he picked up a piece and he was able to do it. We all just relaxed then and became friends.*

Sharing the experience with memory improvement

Many of the participants reported some improvement in their memory, for some it was quite significant, for others it was less so. Those who found their memory had improved also described how it improved their sense of well-being and had given them more confidence.

It does help the memory. They use to say come on Jane, and I would say that's that and they would say you did well Jane you did very well. I use to feel so good (Jane).

I have improved quite a bit and I feel good about it (Colin).

I have memory problems. I forget names of people. Don't worry they said to me. I now have learnt the names of some members of the group (Mary).

Alex response illustrates the complexities of living with memory loss when he was asked if he had noticed any improvements in his memory; *I'm not sure I think I have, but the girl (CST practitioner) told me I had improved quite a bit. I felt good about that. But I didn't really know before that.*

(iii) Socialisation

All participants described at length the social aspect of the group. It would be fair to say that it was a major attraction for participants to continue to come to the group. For many the social aspect of the group was as important, if not more so, than the activities. This was reported as enjoying the company of the others, meeting people, and a reason for getting up in the morning.

There was definite consensus among the participants that it provided fun and enjoyment and a place to have a chat and cup of coffee.

Having fun...I got a lot out of it... we have a lot of laughs; ...Saw it as a chat group; loved having the people around me; it could have gone on forever I loved it that much.

Company of others

The participants clearly related to each other and looked forward to the CST sessions. Some of the participants looked forward to attending the sessions and reported how they would prepare for the session the following day. One participant prepared photos; several others asked family members to Google search information; while others laid out their clothes in preparation for the next day.

It's a day out and I look forward to it; like the group and meeting the other people (Sue).

I was so glad to be going to the meetings. I enjoy the company and the socialising. I couldn't handle it before sitting around all day... We have developed a bond between us (Grant).

While I attended the sessions in the company of the others I was able to forget about what was happening at home (Colin).

Another participant, who had been admitted to a retirement facility while attending the CST programme, found coming to the group was: *the only stimulation I have now, I can listen to intelligent conversation. I have got nobody to talk to back at that place it's very depressing (Audrey).*

Families

(i) Benefits of CST programme

Semi-structured interviews were conducted with eight family members, including six spouses and two siblings. They were primarily asked about perceived benefits during and following the CST sessions, and other practical information.

Families of younger participants reported that they had been struggling to find activities or groups suitable for the participants. They had visited groups or contacted community groups with disappointing results:

I rang several places looking for a day care. I had no knowledge of where to go to. I was struggling (Linda).

It was these same families who found the participants had the 'switch go on' and were verbally more responsive following the sessions.

I was surprised what he talked about; he would come home and phone our daughter to seek information (Sarah).

Several others found family members were more engaged and less inclined to sit and stare at the computer when they came home from a CST session.

Previously she would open up the computer to do Code Break game and just stare at the screen for three to four hours, now she is back into actually playing the games (Peter).

(ii) Information sharing

Some of the families stated they were a little frustrated as they had not been provided with details of the sessions. They felt this would have been helpful as they would often talk on the way home but didn't really know what they were talking about. As one carer reported, *he was talking about things from the past but I had no idea what he was relating it to so it was a bit frustrating and added to my already stressful day (Mary)*; and Joan relayed that *someone needs to write down the overview of material covered in session so that they can so we can talk about it. At the moment you wonder if it comes up in the conversation (Linda).*

Other families described how they would have liked to visit the hall to be sure the participant was aware of the bathroom and other facilities. Another family member reported that it was a complete mystery what happened during therapy.

I didn't know what they did in there (the hall) I wanted to go in but I felt I couldn't. I felt a bit cross about that to be honest (Peter).

One family member went to great lengths of searching the pockets of her partner when he got home from CST to get clues about the session activities.

I would look through his pockets to find scrapes of paper that might have words or other stuff so I knew what he was talking about (Sarah).

One carer suggested that *the facilitator [CST practitioner] needs to write down what occurred in the group so we can talk and know about it if it comes up in conversation* (Noeline).

(iii) Outlays

While the CST was delivered freely to participants², carers reported accruing CST attendance costs which were described either as financial or costs in terms of families' time.

(iv) Transport

Transport was a major concern for most participants and their families. For some families it was the actual cost of petrol or taxis. As one carer stated; *it's a shame it was so far away, the sessions needs to be closer to our area. It created some financial stressors for us* (Peter).

For others it was cost in terms of time. Driving to and from the venue was considered a waste of time due to sessions being only an hour. Because of this most families found it far easier to just wait in the car park as Linda explained; *I just stayed in the car park and read a book while I waited*.

Waiting in the car park provided an opportunity to network with other families which they found to be beneficial.

I waited in my car and then we carers started chatting together and sharing stories so it turned out to be useful as I got to know the names of the others participants that he might talk about on the way home (Sarah).

Sadly because of travel costs and venue location, several participants and families declined to enrol in the maintenance programme. All participants had requested them in response to the overall positive benefits they had experienced.

CST Practitioners

The CST practitioners' perception of the impact of CST is from their lens of observed differences in the CST programme participants during the sessions. The practitioners provided a standardised CST programme as outlined in the CST manual. They grew in confidence as the sessions progressed and this confidence was clearly reflected in the participants as they came together as a group. They witnessed over the seven weeks how participants relaxed and started to open up after the first couple of sessions. They attributed this to supportive mechanisms and the structured content of the CST programme.

(i) Supportive Mechanisms

The group environment provided a supportive and safe place for the participants to contribute and talk about themselves. They noted differences both subtle and more obvious in each participant. As one practitioner reported; *some of the participants really changed over time and loved coming* (Barbara) as well as noting for one reluctant attendee once they became engaged in the activities. This allowed them the opportunity to forget about the worries at home.

One man who just didn't want to come when I visited him at home – I could see joy and he was beaming. I felt he was able to forget all about his problems at home (Barbara).

² It was part-funded through collaboration between Alzheimer's Auckland Charitable Trust and the University of Auckland.

(ii) Working Together

Providing a supportive environment for participants also meant providing ways for participants to work together on their activities.

One practitioner described how she was concerned about bringing strangers together and getting the team games underway. She was amazed how quickly they came together as a group and supported each other.

As some of the activities were team based my concerns were unwarranted, for within 2-3 sessions they were all supporting each other and working together. I was surprised how quickly that happened (Sue).

She also noted how participants were supportive of each other when personal matters or concerns were raised by any of the participants. For example Sue who had been admitted to an aged care residential facility, but still attended the group sessions noted that *the group were concerned and supportive as they discussed her problem (Sue).*

(iii) Being resourceful

One practitioner was experienced in delivering CST and felt the sessions were adequate in time.

I thought the time allocated of an hour was adequate as sometimes the group flagged and needed new ideas generated to keep them interested (Barbara).

This is in contrast to the participants and families who would have preferred the sessions to be a little longer with some suggesting two-hour sessions.

Running the sessions from a public venue was considered cost-effective and also provided good access and parking. However, this meant all resources needed to be externally brought in. The lack of internet access was seen as a particular drawback. As explained by one group practitioner; *having an iPad to use in the group would have helped with especially with the current affairs information (Sue).*

Having access to internet access was seen as essential for younger CST practitioners.

I would often use my iPhone to check local news or national historical information when there was some discussion that needed validating or a debated view needed clarification (Emma).

Case studies

Case 1:

Aroha is a Maori woman in her early 50s. She shares her home with her partner and several grandchildren whom Aroha and her partner provide support and care for. Aroha was diagnosed with vascular dementia in her mid-40s. Her behaviour had been quite unsettling for some time. She was loath to engage in social activities, and experienced separation anxiety when her partner went out. For example, she repeatedly phoned her partner to find out where she was and when she would come home. Over the previous year Aroha had become increasingly unhappy and despondent. She didn't get any benefit from taking an antidepressant medication started by her family doctor six months earlier. Eventually her distress became aggression. There were several episodes of verbal aggression and the grandchildren became cautious of their Nana.

When her partner first heard of the CST programme offered by Alzheimer's Auckland Charity Trust and suggested this to Aroha, she was very distressed and said she was being forced into this activity. However, from the first CST session Aroha has been a loyal attendee. In anticipation of attending the group, she gets her clothes ready the night before so she is ready the next day for the session. Her low mood appears to have resolved. She enjoys the socialisation in the group and is spontaneous and effusive in her interactions. The episodes of aggression and separation anxiety also resolved. Aroha and her partner relate this to the enrichment provided in the group. Aroha is very happy, as are her partner and family, that she is involved in the CST programme.

Case 2:

Will is one of the older participants in the CST programme. He lives with his wife in a flat attached to his daughter's home. He and his wife spent many years actively involved in supporting and entertaining older people in the community and within their church. However, when Will was diagnosed with dementia, he became very reluctant to socialise and engage with others. His motivation also reduced. While his wife continued to be actively involved in the family and the church, Will was content with sitting in front of the computer, seemingly occupied for long hours.

When Will first started the CST programme, he was quiet and disinterested. In the third week he became interested in what other participants had to say; he made jokes and was actively engaged in the group. Other participants (and Will's wife) have described that *...it was like a light went on in that man*. His wife reported that he came home telling her about what other people had shared and what activities they had done. Will and his wife had become emotionally distant as his dementia progressed. However, with attending the CST programme, Will has once again become interested in expressing his affection and this is the most noticeable change observed by his wife. Will loves attending the group and his wife is grateful for the positive change.

Case 3:

Robert is in his late 80s and lives in an aged care residential facility. He came to the facility following two major strokes which resulted in some physical disabilities and cognitive impairment. While a resident in the facility, notably, Robert was reserved, quiet, and initiated little conversation. His wife had noticed over some time that he had become increasingly despondent and withdrawn from both her and the family. He sat and allowed things to happen around him without involving himself.

Robert has changed significantly since he completed the seven weeks of CST programme. He is now alert, reactive and talkative. He enthusiastically engages other residents at the facility, including those who do not attend the CST programme. During a CST session he is interested and enthusiastic about the topics discussed. Once the session finishes, he phones his son and asks him to Google search more information, which he takes to the next group for discussion. This may be because one of the CST practitioners Google searches information during the session as additional stimulation for the group. Robert has become emotionally engaged with his wife and son again. Recently they were both seen embracing and talking about the contents of the CST programme. Robert, his wife and staff at the facility are all very pleased with this positive outcome.

Conclusions and recommendations

Discussion

The overall aim of this project was to pilot CST groups in both community and residential care settings to assess its acceptability in the New Zealand context

This study found that depressive symptomatology in the aged residential care facility CST group improved following a course of CST.

The Cochrane review did not find that CST had an effect on mood (Wood et al., 2012). In this pilot study, the GDS-15 was used to measure mood and level of depressive symptoms of our participants in the residential care CST group. Despite the very small sample size the GDS-15 was the only statistically significant result found in this study. Although the prevalence of depression in aged residential care facilities has never been systematically studied using GDS-15 in New Zealand, a recently published Australian report suggested that just over half (52 per cent) of all permanent aged care residents had symptoms suggestive of depression (Australian Institute of Health and Welfare, 2013). It is possible that some of the non-specific factors of CST (for example, social engagement) had a positive effect on mood in our participants. The improvement in mood might also partly explain the 'switch-on' phenomenon found in the qualitative evaluation.

The MMSE and ADAS-Cog were used to measure cognitive function of our participants in the community and residential care CST groups. We found an average increase of 0.3 points on the MMSE and 2.0 points on the ADAS-Cog in all participants following treatment with CST. Although neither of these results was statistically significant, the amount of change on the ADAS-Cog was comparable to the results in the Cochrane review (Woods et al., 2012). The Cochrane review found an average benefit of 1.7 points on the MMSE and 2.3 points on the ADAS-Cog and with CST.

There was also a positive trend in quality of life of participants as reported by their families, but not on the participant self-reported quality of life measure. However, positive changes in psychological well-being were captured in interviews with participants.

It is worth noting that not all 15 trials included in the Cochrane review used the same CST protocol as described in the CST manual (Spector et al., 2006). The 'dosage' of cognitive stimulation received also varied greatly. For example, the duration of the intervention varied from four weeks to 24 months, with the sessions varying from 30 minutes to 90 minutes. The median frequency of the sessions was three times a week. In addition the cognitive stimulation activities were different.

Most of the published CST trials were published by the same research group at the University of College London. More recently two CST studies have been conducted in other countries. In Ireland Cohen et al. (2011) studied 15 participants who received CST vs 13 controls. They found a significant improvement in MMSE scores (CST group: +0.8 vs controls: -2.1, $p=0.01$) and a trend in improvement in quality of life (QOL-AD) (CST group: 3.6 vs controls: 0.5, $p=0.06$). In Japan Yamanaka et al. (2013) compared 26 participants in the treatment group with 30 participants in the control group (Yamanaka et al., 2013). They found a positive improvement in cognition (MMSE and COGNISTAT scores). However, statistically significant improvement in quality of life was found in only one of the four measures (EQ-5D proxy: $p<0.05$; EQ-5D self: $p=0.78$; QoL-AD proxy: $p=0.06$;

QoL-AD self; $p=0.67$). Although their sample size was relatively small, Yamanaka et al. calculated this using a power of 0.8 and effect size of 0.4. Our study did not find any statistically significant improvement in quality of life but we had a small sample size.

Four key issues were identified in the qualitative evaluation: transportation, family involvement, technology and the 'switch-on' phenomenon.

(i) Transportation

Transportation is often identified as a barrier in community programmes for older people. It is more of an issue for people with dementia who often lose their capacity to drive and have to rely on their families for transportation. Transportation should be considered when planning a new CST programme in the community. CST practitioners have to be resourceful with the availability of various community resources. For example sourcing total mobility scheme taxi vouchers, volunteer drivers and community vans. Needs assessment services in some DHBs currently fund shopping services for disabled older people where a paid care staff member drives the older person to a local shop or supermarket. A similar funding arrangement may be possible to enable people with dementia who attend a CST programme.

(ii) Family Involvement

Families who wish to be involved could be provided with additional information on CST. An orientation session prior to the CST programme, would be beneficial for both families and participants so they can be socialised to the programme. The orientation could provide an outline of the CST programme, and facilitate discussion on the expectations of both CST practitioners and families. Families can also become familiarised with the structure and themes of CST by reading the CST manual.

At the conclusion of each CST session, CST practitioners can provide families with a summary of the events and activities covered in the session. Families can be involved in the delivery of CST but its effectiveness is still being investigated. Orrell et al. (2012) are currently conducting a multi-centre, pragmatic randomised controlled trial, to evaluate a home-based individual CST programme, delivered by family carer for people with dementia (Orrell et al., 2012). During the CST sessions, family members could be provided with tea and coffee in an informal meeting setting.

(iii) Technology

The inclusion of technology has not been formally evaluated as part of CST but this study has highlighted that it would add value to obtaining information during the sessions. For example electronic devices such as tablets, smart phones and computers may further increase the stimulation available in a CST session. Many participants in this project were still engaged with computers.

(iv) The 'switch-on' phenomenon

A number of participants in this study became more communicative and sociable as evident in the interviews with family members and facilitators. Spector, Gardner and Orrell (2011) noted in an earlier study that the most commonly reported cognitive changes were an improvement in concentration and alertness, described by participants and carers as a sense of being more 'switched on' or wanting to attend to things more.

In this pilot study we did not select a specific quantitative outcome measure to capture the 'switch-on' phenomenon. However, previous CST studies have included the assessment of communication and social interaction (as one of the secondary outcomes) using instruments such as the Holden Communication Scale

(Holden & Woods, 1995). In their Cochrane review, Woods et al. (2002) found a moderate effect size of 0.44 with participants in the CST groups showing a significant improvement in this area (Woods et al., 2002).

There is growing evidence that social engagement has a positive effect on cognition in older people with dementia (Blankevoort, van Heuvelen & Scherder, 2013; Bossers et al., 2014). The Honolulu-Asia Aging Study (1965-1997) measured social engagement in a cohort of older Japanese American men ($N=2513$) (Saczynski et al., 2006). The researchers found that decreased social engagement was a risk factor for developing dementia. In a longitudinal study of 2812 community-dwelling older people also found that a reduction in personal networks was a significant factor in cognitive decline (Ellwardt, van Tilburg & Aarsten, 2014).

Older people who had a variety of contacts such as, family, clubs, and other organisations were more likely to maintain their level of cognitive functioning. A recent study of 153 U.S. nursing home residents with dementia found that the lack of social engagement was associated with a lowered perceived quality of life, higher mortality and a decline in functional level (Kang, 2012).

CST offers regular social engagement with a small number of previously unknown individuals twice a week for seven weeks in a structured manner. In a cross-sectional survey, Miranda-Castillo, Woods and Orrell (2013) found that the most frequent unmet needs for people with dementia were psychological distress (including loneliness, confusion, worry and anxiety), followed by the need for daytime activity and company.

Thacker (2012) argues that social engagement (as a non-specific factor) may be as important as the active ingredients of CST. Control groups in CST research often receive 'usual' activities, which generally means inactivity. Yuill and Hollis (2011) systematic review suggested future studies should include a placebo control group where participants would receive the same amount of attention as the treatment group to examine the impact of social engagement alone.

Modifications of Cognitive Stimulation Therapy

This pilot project has shown that very few modifications were required to deliver CST in the New Zealand setting. The ability to retain CST in its original format has the advantage of ensuring its internal validity without comprising its external validity.

Training and competency

RECOMMENDATION 1: Development of a CST training and accreditation programme in NZ

This pilot project has highlighted the crucial role of CST practitioners in the implementation of a CST programme. The developers suggested that CST can be administered by a range of health professionals working in dementia care, for example nurses, psychologists, care workers and occupational therapists. There is currently no recognised CST training programme in New Zealand. The CST developers recommend attendance at a one-day training workshop that involves didactic teaching, group discussion, exercises, video observation and role-play. A step-by-step manual (Spector et al., 2006) is also available and this was one of the resources for CST practitioners in this project.

A systematic review of 15 cognitive stimulation trials found that they were delivered by therapists with a variety of backgrounds, experience and training (Aguirre et al., 2013). However, this review did not find indications in relation to the required amount or type of training necessary to run cognitive stimulation in an effective way.

The competencies required to deliver CST have not been developed in NZ or overseas. CST can be delivered by a range of health professionals and volunteers who have different prior learning and experience, some of which are generic competencies and can be applied to the delivery of CST. The mapping of these CST competencies is a priority as part of the dissemination of this evidence based treatment. These competencies are likely to fall into three categories:

- (i) knowledge – for example the content and principles of CST
- (ii) skills – for example small group facilitation
- (iii) attitudes – for example person-centred approach in dementia care.

Once the competencies are agreed upon, training and assessment can be developed to align with them and to ensure CST is delivered consistently across localities. A formal accreditation programme can be part of this process for maintaining the quality and standards of CST practitioners. CST practitioners will also benefit from a programme for maintaining their competencies, continuing education, and professional development. Online discussion and webinars are some of the ways for CST practitioners to stay connected with each other.

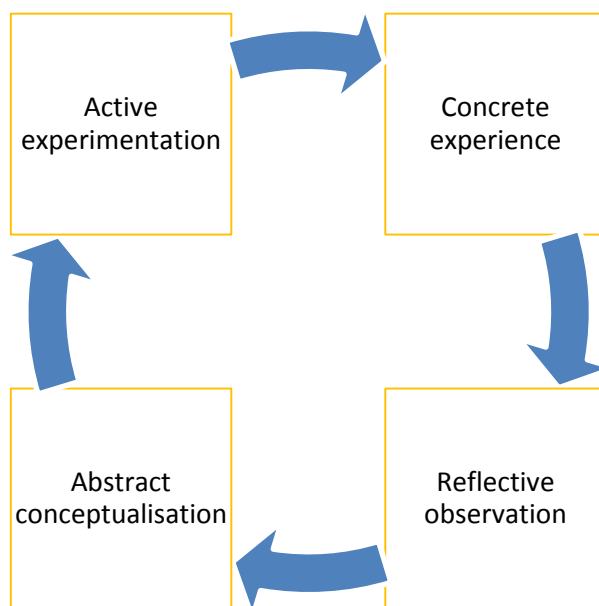
In this pilot project an occupational therapist, nurse manager, enrolled nurse and volunteer with varying clinical experiences were successfully trained to deliver CST groups. The training used in this pilot was based on experiential learning (Figure 1) and adult learning principles.

The training activities (see page 14) can be further developed, refined and evaluated in future work on CST competencies development and training in New Zealand. Given the availability of technology and travel issues in rural parts of New Zealand, e-learning should be considered for teaching and learning activities.

It is the intention of the project team to develop a training and accreditation programme in New Zealand. Such a programme will increase the number of competent CST practitioners who can translate this evidence based treatment in various clinical settings in New Zealand. More people with mild to moderate dementia across health settings will therefore benefit from this treatment. Future collaboration with Te Pou could address knowledge exchange and workforce development in this area.

Figure 1:

Experiential learning principles.



Implementation of CST in DHBs and other health care settings

RECOMMENDATION 2: DHB Dementia Care Pathway to include CST as a treatment option

This pilot project has successfully implemented three CST groups run by a charitable organisation and an aged residential care facility. There is the initial set-up cost (for example, equipment and manual) and ongoing costs (for example, staffing and venue). However, the main resource required in delivering CST is the availability of a competent practitioner. Spector, Orrell and Aguirre (2012) examined the uptake of CST by staff who attended a one-day workshop in the U.K. They found the group taking up CST had better learning characteristics; and simple factors such as a lack of staff time and resources may prevent people from implementing CST in their centre.

CST can be readily adopted in various clinical and health care settings to support people with a mild to moderate dementia. The availability of a group of competent CST practitioners will immediately improve access to this treatment modality in New Zealand.

Each DHB in New Zealand is committed to implement a dementia care pathway. DHB funders and planners, and clinical leaders are very much involved in the development of these pathways. CST should form part of a dementia care pathway and be readily available for people with mild to moderate dementia. Given the different clinical resources and governance structures, DHB funders and planners should consider the best service provider to deliver CST in their locality, and take into consideration the transportation and family involvement issues highlighted in this pilot project. CST can be delivered by DHBs (for example, Hawke's Bay DHB), charitable organisations and residential care facilities.

As an example, the Northern Regional Clinical Pathway for the Management of Cognitive Impairment was recently launched (see Figure 2). The Northern Region includes Northland, Auckland, Waitemata and Counties

Manukau DHBs. Following a diagnosis of mild to moderate dementia, a referral to a CST lead provider could be included among other usual dementia management in this primary care based decisional tool.

Maintenance CST

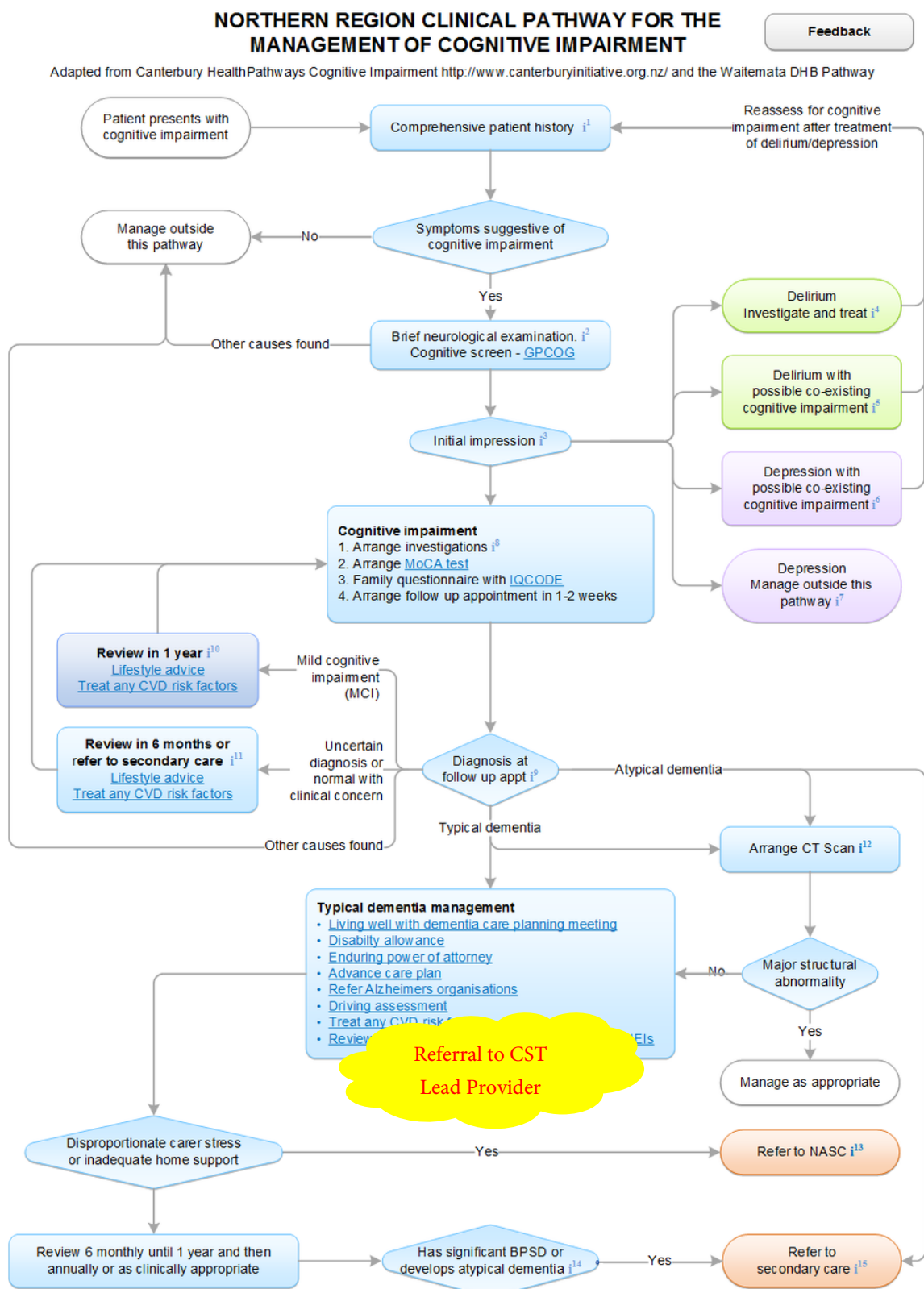
RECOMMENDATION 3: Establish Maintenance CST Programs

Both Alzheimer's Auckland Charitable Trust and Radius Taupaki, the aged care residential facility, decided to continue with the CST maintenance treatment which involves another 28 weekly sessions (Aguirre et al. 2012). Funding will be sought to evaluate the outcomes at 28 weeks. These two organisations have valued the importance of translating research evidence to clinical practice. People with dementia supported by these organisations are already benefiting from CST. The CST practitioners in these two organisations will continue to receive support from the project leads beyond the scope of this pilot project.

Literature on the benefits of maintenance CST is lacking. However, an ongoing programme (with a detailed schedule of reinforcement and follow-up) is required for cognitive stimulation to have more lasting effects (Aguirre et al., 2013). Orrell et al. (2014) recently reported a single-blind, multi-centre, pragmatic randomised controlled trial investigating the benefits of maintenance CST. Both the intervention and control groups received the initial 7-week, 14-session CST programme. The intervention group then received weekly maintenance CST for 24 weeks. The control group received usual care. They found self-reported quality of life (on the QOL-AD) was significantly better for the intervention group receiving treatment at six months; whereas improvements for proxy-rated quality of life and activities of living were only evident at three months. Of note, only the intervention group taking acetylcholinesterase inhibitors had cognitive benefits (on MMSE) at three and six months. This suggests that combining CST and anti-dementia medication has better long term outcomes.

Figure 2 :

Northern regional clinical pathway for management of cognitive impairment (Healthpoint, 2014)



Northern Region Clinical Pathway for the Management of Cognitive Impairment May 2014. For review May 2016
Please [click here](#) to view the development team for the management of Cognitive Impairment

Limitations

One of the main limitations of this pilot study was the lack of a control group of participants who did not receive CST. This can explain the negative findings in the quantitative measures of cognition and quality of life. The positive finding on the Geriatric Depression Scale (GDS) may be the result of a type-I error³. In addition the GDS in our two community groups was not administered. As the project team followed the recommendations of the Ethics Committee to limit the number of outcome measures in our community-dwelling participants.

Future research

A multi-centred New Zealand CST research programme to establish the efficacy of CST in the community and aged residential care settings

It is important to replicate the benefits (cognition, quality of life and communication) of CST found in overseas studies in the New Zealand setting. It is also important to determine whether the results are generalizable to other clinical settings and population groups (e.g. different ethnic groups) In addition, social engagement should be included as a comparison arm in future CST randomised controlled trials. This will clarify the role of social engagement as a non-specific factor in CST.

The 'switch-on' phenomenon previously mentioned warrants further investigation. For the participants, families and CST practitioners, this phenomenon is often a more satisfying outcome than cognitive improvement and therefore could be considered as a primary outcome in future CST studies.

Being older and female was associated with increased cognitive benefits from the CST intervention (Aguirre, Woods, Spector & Orrell, 2013). However, other predictive clinical factors have not yet been systematically investigated to identify people who benefit the most from CST. Future CST studies can investigate whether certain subtypes of dementia, biomarkers and neuroimaging findings can predict response to CST. It is also unclear in the literature which CST components and/or activities are responsible for its benefits. Once researchers are able to identify a dose-response relationship, the effectiveness of CST can be enhanced by including more of these active components and activities during treatment.

A CST research programme in New Zealand will be developed by the project team. Such a programme would address the knowledge gaps mentioned in this report and further improve this treatment for people with mild to moderate dementia.

³ Type I error is sometimes called a false positive result.

Appendix A: Hawke's Bay DHB site visit

We undertook this site visit in November 2013 as part of the preparation for the CST groups in Auckland. The site visit activities included:

- 1) interview with two CST trained occupational therapists.
- 2) participation in a maintenance CST group.
- 3) interview with a service user with dementia and her husband. This service user had received CST treatment.
- 4) interview with the manager and a CST practitioner at Alzheimers Hastings.
- 5) meeting with the Older Persons Mental Health team based at Hastings Hospital.

(1) Background

CST was introduced in Hawke's Bay in 2009. A senior doctor came across this treatment modality while she was attending a conference in the U.K.. She advocated for this treatment when she returned to Hawke's Bay. A business case was put forward and accepted by the Hawkes's Bay DHB.

A full time occupational therapist is employed to deliver CST (initial treatment and maintenance treatment) and oversee the *Bridging programme* run by Alzheimers Hastings. As a service CST is embedded within the Older Persons Mental Health team.

CST groups are offered three days a week by the Hawke's Bay District Health Board.

Monday Two initial groups and one maintenance group

Tuesday Three maintenance groups

Thursday Two initial groups and one maintenance group

This is the maximum capacity that can be provided by one CST practitioner.

(2) Referral and assessment process

- The Hawke's Bay CST programme is aimed for people with mild dementia (in general a MMSE score of 20 or above). They generally do not have any significant functional impairment and live in their homes, including retirement village units.
- Referral sources include GPs, Older Persons Mental Health team, geriatricians, and any other health service providers. There has been no self-referral.
- There is no age limit and people with young onset dementia are included.
- Following a referral a CST practitioner undertakes an assessment at home over three sessions. The assessment includes past social and occupational history, current daily routine, functional and language impairment and Cognistat (a bedside cognitive screening test). The CST practitioner provides an explanation of the Cognistat results and the CST process. Early engagement of the service user and whanua/family is a crucial part of the assessment phase.
- To monitor outcome, Cognistat is repeated following the initial CST treatment (seven weeks).
- Service users are put on a waiting list until a new group commences. The waiting time can be up to six weeks, depending on the timing of the year and the number of new referrals.

- A copy of the assessment is forwarded to the referrers and/or GPs.

(3) Initial treatment and maintenance treatment

- The initial treatment includes seven weeks of twice weekly sessions.
- Maintenance sessions are offered upon completion of the initial treatment. The duration of maintenance treatment varies, depending on the needs of the group and the composition of the group. Maintenance sessions generally run for four to six months but it can run for 12 months. Maintenance sessions are usually not offered when the service users become too functionally impaired. In some cases service users have stopped attending when they lost their driving licences as transport had become too much of a barrier for them.

(4) Bridging programme

- Following completion of the maintenance treatment, service users are referred onto the bridging group run by Alzheimers Hastings. The bridging group runs for 90 minutes every week. It has the same structure as the initial and maintenance treatment. The duration of the bridging group varies and can last for 12 months. This bridging programme supports clients with transition and integration into the day programme.
- Following completion of the bridging group, service users can join the day programme run by Alzheimers Hastings. Alzheimers Hastings runs a day programme (on the same site) five days a week. The day programme is funded by the DHB.

(5) Structure of the CST groups

- Each group includes six participants.
- The group runs for 60 minutes instead of 45 minutes in the manual.
- Attendance and retention is generally high with participants often arranging their other activities during the week around the CST groups.

(6) Role of the CST practitioner

- The CST practitioner in Hawke's Bay is funded by ring fenced mental health Blueprint funding. She is part of the Older Persons Mental Health team based at Hastings Hospital.
- In addition to delivering CST groups, the CST practitioner has a navigating role which includes liaison with clinical and support services, support for families, crisis advice and advice on driving cessation.
- The CST practitioner also provides education on dementia to the local GPs. The dementia care pathway in Hawke's Bay DHB is based on primary care diagnosis.
- There is only one CST practitioner and peer support can be an issue. The current CST practitioner receives support from the clinician who previously worked in this role.

(7) Training of CST practitioner

- The “train the trainer” model is used for novice practitioners. For example, the CST practitioner at Alzheimers Hastings has no clinical background or prior experience with running groups. She was a CST co-facilitator for four to five months prior to facilitating the bridging group.
- CST practitioners are required to be flexible and adapt to meet the needs of group members. Each group is unique in terms of its composition and dynamics.

(8) Adaptation of the CST manual

- The first session is designed to provide psychoeducation on dementia.
- There is also a session on psychoeducation for whānau/families.
- Peer support appears to be an important element of the group.
- A theme song is not included because it was not well received when it was trialled in the first group.
- The CST practitioner monitors and responds to the psychosocial needs of group members.
- A number of activities (for example, card games) are modified for the New Zealand context.
- The principles of CST are maintained while the CST practitioner is required to adapt the manual to meet the needs of the service users. A flexible approach is taken, rather than strictly adhering to the manual.

(9) Other resources:

- Service users and their whānau/families arrange their own transport to attend the CST groups.
- The Napier groups are run from a DHB health centre and the Hastings groups are run from Hastings Hospital.

Appendix B: Semi-structured Interview for people with dementia

1. Tell me about your experience of the group?
2. What prompted you to join the group?
3. Did you have goals you hoped would be achieved in attending the group? What were they? Were your goals achieved?
4. What part of the group did you enjoy?
5. What parts of the group were less satisfying and why?
6. What benefit did you feel the group provided to you?
7. What benefit do you feel the group provided for your family?
8. Were there aspects of the group which were missing, or you consider could have been done differently?
9. Was seven weeks enough? Would there be value in a further 16 week – 24 week group? And what would be gained by a longer group?
10. What assistance if any did the group play in helping you adjust to the diagnosis of dementia and your future?
11. Did you have supportive contact with staff outside of this group and what for did this take?
12. Psychological distress*, daytime activity and company are identified as the most important “unmet” needs for people with memory problems:

Do you think that the group helped you address any of these needs?

*Psychological distress refers to negative feelings such as anger, sadness, loneliness, confusion and worrying

13. Do you intend engaging with members of the group outside of the group?

Appendix C: Semi-structured Interview for families of people with dementia

1. How did you and your relative become engaged in the project?
2. What benefits did you believe your ...would gain from your being part of this group?
3. What benefits did you think that your gained from your...being part of the group?
4. Describe any changes you feel occurred with your...being part of this group?
5. Describe any changes you feel occurred with your relationship as a result of ...being part of this group?
6. Were there aspects of the group which were missing or you consider could have been done differently?
Including issues such as structure / access / timing?
7. What assistance (if any) did the group play in helping you and your ...adjust to the diagnosis of dementia and your future together?
8. Was it important for you, and was your...involvement in the group communicated to your GP?
9. Did you or your ...receive any other support while your...was engaged in the group, and what form did it take?
10. Are there opportunities for further socialization outside of the group, and what are they?
11. Was seven weeks enough? Would there be value in a further 16 week – 24 week group? And what do you think would be gained by a longer group?
12. Daytime activity, company and psychological distress are identified as the most important unmet 'needs' for people with memory problems, (identified by carers)*:

Do you think that the group helped your...address any of these needs

*Psychological distress refers to negative feelings such as anger, sadness, loneliness, confusion and worrying.

Appendix D: Semi-structured Interview for staff delivering CST

1. Describe the benefits people with dementia gained as a result of being part of the group?
2. Describe the benefits their families received as a result of being part of the group?
3. What observable changes did you see for participants during the group?
4. What observable changes did you see for families during the group?
5. Were there aspects of the group which were missing, or you consider could have been done differently?
6. Daytime activity, company and psychological distress* are identified as the most important unmet 'needs' for people with memory problems, (identified by health professionals):

Do you think that the group helped the participants address any of these needs?

*Psychological distress refers to negative feelings such as anger, sadness, loneliness, confusion, and worrying.

7. What could have improved the ability of the group to achieve these?
8. Was the training you received before running the group adequate?
9. What was good and what was unsatisfactory about the training?
10. What skills do you believe that you have that enabled the group process?
11. What skills do you think need improvement to enable the group?
12. What barriers were there to carrying out the group e.g. access, structure, timing?
13. Is Cognitive Stimulation Therapy enough? Or would it be better included as part of a number of supports for people with dementia and their families?

Appendix E: Cost summary (Alzheimers Auckland, 2 CST Groups)

Staffing Costs	hours spent	cost per hour	Total costs	
Occupational Therapist				
set-up time	10	\$ 37.80	\$ 377.95	
group time	35	\$ 37.80	\$ 1,322.84	
travel time	14	\$ 37.80	\$ 529.14	
mileage	22 km per group		\$ 237.16	
Socialisation Worker				
group time	35	\$ 27.39	\$ 958.57	
travel time	14	\$ 27.39	\$ 383.43	
mileage	44 km per group		\$ 474.32	
Operations Manager				
set-up time	10	\$ 52.60	\$ 526.04	
Venue Costs				
INRF Facility				
per group booking	\$41		\$ 579.60	(GST inclusive)
Transportation costs				
taxi costs			\$ 1,355.74	(GST inclusive)
Tea/Coffee/Biscuits				
per group	\$5		\$70.00	
Total costs to implement CST project			\$ 6,814.79	

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